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When Resilience Fails

The Political Economy of Treatment Seeking Behaviour and Impact of Direct Cost/OPPs on Households of People Living with HIV in Harare Metropolitan Province, Zimbabwe

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**When Resilience Fails: The Political Economy of Treatment
Seeking Behaviour and Impact of Direct Cost/OPPs on
Households of People Living with HIV in Harare Metropolitan
Province, Zimbabwe.**

By

Phillip Matululu Nyahoda

**A thesis submitted for the degree of Professional Doctorate in
Health**

University of Bath, United Kingdom

Department for Health

January 2017

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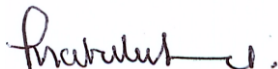


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Acronyms

AIDS	Acquired Immunodeficiency Syndrome
AMPTO	Assisted Medical Payment Treatment Orders
ARV	Anti-retroviral Drug
BEAM	Basic Education Assistance Module
ART	Anti-retroviral therapy
CAM	Complementary alternative medicine
CD4	Cluster Differentiation 4
CD8	Cluster Differentiation 8
CHAI	Clinton HIV and AIDS Initiative
CIDA	Canadian International Development Agency
DFID	Department for International Development
ESP	Expanded Support Programme
GDP	Gross Domestic Product
GFTAM	Global Fund for AIDS, Tuberculosis and Malaria
HIV	Human Immunodeficiency Virus
ILO	International Labour Organisation
IPA	Interpretative Phenomenology Analysis
LFT	Liver Function Test
MDG	Millennium Development Goal
MOHCC	Ministry of Health and Child Care
MSF	Medicins San Frontiers
NAC	National AIDS Council

NATF	National AIDS Trust Fund
NFM	New Funding Model
NGO	Non-Governmental Organisation
OIs	Opportunistic Infections
OPP	Out of Pocket payments
PAYE	Pay As You Earn
PICES	Poverty Income Consumption and Expenditure Survey
PLWH	People Living with HIV
RBF	Result Based Financing
SADC	Southern African Development Community
SDGs	Sustainable Development Goals
SIDA	Swedish International Development Agency
TB	Tuberculosis
TCPL	Total Consumption Poverty Line
TSB	Treatment Seeking Behaviours
UNDP	United Nations Development Programme
USG	United States Government
USG	United States of America Government
UNAIDS	Joint United Nations Programme on HIV/AIDS
VAT	Value Added Tax
WFP	World Food Programme
WHO	World Health Organisation
ZHAAUCT	Zimbabwe HIV and AIDS Union Community Trust

Abstract

Background: The availability and coverage of Anti-retroviral therapy (ART) has increased and led to reduced morbidity and mortality in Zimbabwe and Southern Africa in general. However, direct costs and socio-cultural factors that influence treatment seeking behaviour (TSB) continue to impede progress towards universal coverage by leaving behind people in need of treatment. The failure of the current health system due to the crisis of accumulation predicated by the lack of savings and investment has resulted in direct costs/out of pocket payments (OPPs). The direct costs/ OPPs are an obstacle towards equitable access to ART. Socio-cultural factors influence the utilization of services due to stigma and religious beliefs, as they have a bearing on treatment seeking behaviour patterns. Although coping strategies such as the borrowing and selling of assets may have been used to smooth consumption, but they have not been adequate enough to mitigate the direct costs of treatment resulting in resilience mechanisms to fail.

Methodology: A sequential mixed method approach was used to collect data on treatment seeking behaviour patterns, the direct cost of treatments and the effects this had on the average household. At the quantitative level, self-administered questionnaires were distributed to 383 people living with HIV (PLWH) in Harare metropolitan province with a view to find out the treatment seeking patterns, the direct costs/OPPs by service providers, quantify the cost burden of OPPs and the number of PLWH who resorted to coping strategies. At the qualitative level, 16 key informant interviews from this sample were conducted. The aim was to get an understanding and explanation on the consequences of treatment seeking behaviour and how the direct costs/OPPs affected households of PLWH.

Results: The major findings of this sequential mixed method study are at two levels; qualitatively and quantitatively, based on a total of 383 people living with HIV in Harare metropolitan province who completed the questionnaires. The findings based on the 383 people living with HIV who completed the questionnaires reveal that, ninety six percent (95.8%) of them paid to have a Cluster Differentiation 4 (CD4) count test, eighty one percent (81.4%) of them paid for treatment, and sixty three percent (62.9%) of them paid towards transport to access treatment or diagnostic services as respondents reported. Fourteen percent (14.1%) of the 383 people living with HIV in Harare metropolitan province who completed the questionnaires paid for antibiotics mainly obtained from pharmacies without a prescription. Eighteen and a half percent (18.5%) of them reported having paid for other diagnostic tests besides CD4 count. The quantitative results further show that, to mitigate against these direct costs the majority of the respondents used 'hardship financing' through borrowing (92.2%) and selling of assets (74.2%). The qualitative results explain and highlight the impact of direct costs on the physiological needs and on the household budgets of PLWH in Harare

metropolitan province. Consequentially, most households of PLWH are forced into impoverishment and food insecure situations. The situations contribute towards the propensity to seek services of traditional healers by PLWH and they periodically default on treatment, endure multiple untreated infections, engage in transactional sex, self treatment, and work for treatment by young people. Social networks such as family and friends influenced treatment seeking behaviour and they were found to be sources from which PLWH could borrow and or receive money for treatment seeking behaviour.

Conclusion and implications for practice: The political economy prevailing in the country is characterised by a crisis of accumulation. This crisis of accumulation is directly responsible for the development of a large informal sector, a fragile and weak health system due to reduced savings and investment, in addition to the mismanagement of other resources. This has resulted in health shocks that consequently, have brought about borrowing and depletion of assets as a way of households financing their health diagnostics and treatment. This has exacerbated poverty and conditions of ill-health. To reduce the impact of health shocks created by the current crisis of accumulation, there is need to adopt broad policies that are embedded in extensive social protection and accountability. There is need to invest in social and health insurance, rethink the way HIV education is taught, integrate services and broaden the scope of results based financing in the provision of health care for PLWH. This would go a long way in achieving meaningful universal treatment targets of not leaving anyone behind, in particular the realisation of the 90-90-90 transformative agenda.

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Chapter One: Introduction

1.1 Treatment seeking behaviour as a predictor of OPPs and poverty

The market failure in the health sector in Africa has resulted in the failure by the state to provide the required health services and commodities to satiate demand by people who need these services the most. While there may be other causes, such as the socio-cultural factors, they need to be located in the broad ambit of the political economy which shapes and defines social relations of production. The failure by the post-colonial state in Africa to be able to uphold its commitment to the Abuja Declaration and the African Union (2012:5)¹ call for shared responsibility has meant that the state in Africa has not been able to sufficiently fund its health care. This has resulted in limited coverage by those in need of treatment and a loss of confidence in the public health services due to inadequate staff, equipment and commodities. The state failure has seen a niche market developing for the private and informal health traditional providers. This has led to out of pocket payments (OPPs) becoming a norm which has affected the household's ability to reproduce economically or socially. The treatment seeking behaviour choices are a result of not only failed health care markets but systemic socio-cultural issues which prevail in society. The treatment seeking behaviour which is located in the socio-cultural and political economy has a deleterious effect in terms of meeting the desired goal of 90-90-90 (UNAIDS, 2015) which seeks to ensure 90% of those living with HIV know their status; 90% of PLWH receive ARVs and 90% of people on treatment have undetectable viral loads. The essence of achieving the goals rests on leaving no one behind. UNAIDS (2015) has noted that many vulnerable people and PLWH still face profound inequalities and the inability to access treatment undermines this goal. The 90 by 90 by 90 transformative agenda will not be realised unless systemic issues that relate to treatment seeking behaviour and OPPs are addressed. This is because of the complexity of dealing with the relationship between HIV and poverty in that the latter can be both a determinant and consequence of the epidemic. In a bid to reduce new infections and AIDS related deaths, treatment seeking behaviour and the economic burden of illness are intertwined. While ART provision and the realisation of the 90 by 90 by 90 transformative agenda is to be realised, weak health systems which cause OPPs and poverty will need immediate attention.

1.2 Treatment seeking behaviour, OPPs and poverty in Zimbabwe

While Zimbabwe has made significant strides in providing treatment coverage since the first reported case of HIV in the 1980s, it still needs to ensure that those in need of ART are provided with the life-saving drugs in a sustainable manner. However, there are still challenges due to the weak health

¹ African Union (AU) Assembly Decision No: Assembly/AU/Dec.413 (XVIII), requested the African Union Commission (AUC) –to work out a roadmap of shared responsibility to draw on African efforts for a viable health funding with support of traditional and emerging partners to address AIDS dependency response

delivery system which began to strain under the Economic Structural Adjustment programme and almost collapsed due to the economic crisis of 2000-2008. The post white settler state² has struggled to sufficiently fund the response, coupled with high and rising formal unemployment, a growing exponentially informal sector whose income is erratic and a weak public health delivery system. These factors have seen a demand for services shift from public to private health providers. Where health financing has largely been OPPs, user fees and in some cases co-payments means that most people will be further impoverished and will not be able to seek treatment. As coping strategies and other methods of resilience fail, households of PLWH are resorting to use of unproven alternative medications through traditional healers, transactional sex work, staying with multiple untreated infections, work for treatment by young people, proliferation of self-treatment, periodic defaulting on drug and diagnostic treatments. Periodic defaulting on treatment and diagnostic tests can result in sub optimal treatment which can result in treatment failure as Reynolds et al (2003), El-Khartib et al (2011) and Wang et al (2011) have warned; having multiple unattended infections, with young people who should be in college or university, having to work for treatment. The negative impact is not only experienced in terms of the spread of new infections but in stifling the growth and development of embodied human resource investment.

1.3 Rationale for the study

The background to this study provides sufficient justification for this mixed method study. In order not to leave any one behind in terms of treatment and care, given the number of patients on anti-retroviral treatment (AER) both in the public and private health facilities, it is advisable to sustain those already enrolled to avoid patients not being able to access treatment or periodically defaulting. Defaulting leads to complications which are a health risk and are costly to correct. In addition, it is important to ensure that those on treatment continue to have durable viral load suppression kept down. This can only be done if impeccable health systems are put in place so as to arrest the poor from treatment seeking behaviour that impoverishes them. In Zimbabwe, these targets are not being achieved owing to poor governance, and poverty which result in hardships in the financing of treatment.

1.4 Research question

What are the treatment seeking behaviours and patterns among the People Living with HIV on ART in Harare Metropolitan Province (HMP) and what factors influence those ART treatment decisions and responses?

² See Ibbo Mandaza (1987). Zimbabwe the Political Economy of Transition 1980-1986. Darkar: CODERIA Books. For an effective elaboration and discussion of this subject.

1.4.1 Objectives of the study

More specifically the research will seek to find out:

1. What are the direct costs of illness for PLWH in the Harare Metropolitan Province (HMP) in terms of the average costs spent on treatment seeking behaviour per month?
2. Explore the link between treatment decisions and levels of direct costs?
3. What cost burdens are exerted by out of pocket payments on house hold budget? (In terms of whether they are ‘catastrophic ‘payments?)
4. How PLWH manage to cope with these cost burdens and the consequences on household livelihoods as a result of :
 - a) The direct costs of treatment seeking behaviour and
 - b) In terms of their resilience (food security, diminished savings and poverty).
5. What effects do these direct costs have on people’s sustained adherence to ART?

1.5 Structure of thesis

The seven chapters presented herein begin with this introduction chapter, whose purpose is to introduce to the reader the subject of investigation. The aim is to provide an overview of the subject that will be investigated. In this case, the subject is on people’s motivations and reasons for their treatment seeking behaviour and the difficult choices they make when spending to access better care or treatment. This does not preclude the economic consequences that ensue from pursuing such treatment seeking decisions on the house hold livelihoods. The rationale for undertaking this study is provided before the research question and objectives of the study. The chapter ends by providing an overview of how this study will be organised in terms of the chapters and their content.

Chapter two is devoted to providing the contextual background to the study as it has implications on treatment seeking behaviour and the choices made to seek treatment and their consequences. The chapter focuses on the political and economic context and the health systems; in particular, the delivery structures, financing modalities (domestic and external), and quality of health care. The political economic context is provided as it shapes the nature of the health delivery system. The context is important for understanding the treatment seeking behaviour of PLWH and the OPPs including the negative impact on the household’s capacity to reproduce itself. In Chapter three the conceptual framework that guides the study is outlined. The chapter reviews the relevant literature related to the key factors that influence treatment seeking behaviour choices by PLWH on ART and OPPS. These factors will be the basis upon which the study will be built upon in terms of measuring and relating the results.

Chapter four describes the methodology of how the study was undertaken. This chapter justifies the research design and describes the rationale for the methodology adopted in undertaking this

investigation. In particular, the chapter describes how the researcher determined the sample size for both the quantitative and qualitative parts of the study; the data collection tools used and the analysis, ethical considerations and the coding frame work. Chapter five, which is divided into sequential parts provides an overview of the direct costs and treatment seeking patterns (quantitative). The second part, which focuses on the qualitative aspects, provides more information on the coping strategies, the effects they have and the cumulative resultant effects of direct costs and or coping strategies on households. Chapter six is the discussion of the results and how they relate to the literature. The study ends with chapter seven, in which policy recommendations and the basis for future research can be constructed.

Chapter Two: Health delivery in Zimbabwe

The background to situating this study begins with a brief on the political economy of the country. The primordial importance of providing a brief on the political economy first, lies in the fact that health systems do not operate in a vacuum. They are determined by the nature of the political economic system in place. In placing the argument for a political economic approach as the basis on which to contextualise this study, it needs to be borne in mind that technical fixes to contagious diseases and health problems such as malaria, cholera and HIV, if not addressed in a holistic manner, tend to corrode the social and economic capacities of households and communities they affect as pointed out by Johnston et al (2015). The emphasis on bio-medical and behavioural approaches alone outside the context of the existing political economy tends to efface the social production of health and shroud the relationships between poverty, class and disease. This is through the way health is prioritised in the funding required for robust health systems and the desire to moderate against poverty induced health shocks by regulating the health private sector; achieving accountability and ensuring that there is minimal disruption to political, social and economic processes that sustain economic growth and development. The chapter then proceeds to describe the health system/delivery structure; in particular the structure of health delivery, financing mechanisms, quality of care and the extent to which the private health providers have grown. These facets of the health delivery system will drastically influence treatment seeking behaviour which can result in impoverishment and resilience failure.

2.1 Political economic context

At the turn of the 21st century Zimbabwe with a population of 13 million people (Census Report 2012) was one of the two most developed countries on the African continent, besides South Africa³ according to Mlambo (1997:29), Kanyanye and Kondo (2011). Kanyenze (2006) points out that during the period 1980-90 the share of agriculture for Zimbabwe was less at 12.2% of GDP than that of Sub-Saharan Africa (SSA) which averaged 31.6% of GDP. Zimbabwe's share of industrialisation as measured by its share of manufacturing contribution to GDP at 25%⁴ was higher than that of Sub Saharan Africa that averaged 10.4% in the same period. The strong economic growth and the need to redress past injustice witnessed a tremendous growth in the social sector particularly health.

Significant investment in the health sector resulted in an increase in health services both at primary and secondary levels to satiate the supply and demand side of services. The post white settler colonial state can be divided into the following distinct decades as Kanyanze and Kondo (2011), Raftopolous and Mlambo (2009) have provided. These are; 1980-90 being a decade of social development in

³ Angus Madison in Kanyenze et al (2011:3) puts the per capita GDP of Zimbabwe at USD1, 356, compared to China at USD3,421 and India USD1,885 for that period. The above statistics show the level of economic wealth in relation to the now Asian Tigers.

⁴ The above statistics show the level of industrialisation that obtained during this decade.

which the new government sought to ensure equity in the provision of health care services. The period 1991-98 was characterised by Economic Structural Adjustment Programme. Of significance in the era was the enforcement of user fees for health services as part of the cost recovery measure proposed by the World Bank and International Monetary Fund for all social services. The period 1999-2008 saw a precipitation of hyper-inflation which had a negative impact on the delivery of health services as the health system gains made in the 80's were sharply reversed.

For example, in 2008, the annual inflation rate was 11.2 million percentage points according to the International Monetary Fund (2008) and the Reserve Bank of Zimbabwe (2008). It practically cost more to print the money than the money is worth⁵, as noted by Kanyanye and Kondo (2011). The Gross Domestic Product (GDP) growth rate of 2008 was -12.6 percent, more than doubling from the year before (Kanyanye and Kondo, 2011). The per Capita GDP per year remained one of the lowest, at USD\$200. The post-white colonial state was not able to finance both the recurrent and capital expenditures for health services and commodities among other social and economic priorities. It resorted to the printing of additional bank notes. Printing of additional money (M2)⁶ to finance domestic debt due to overspending of available resources at a time income or revenue from both domestic and exports had drastically been reduced and this resulted in excess money supply (M4)⁷. Zimbabwe begun to import maize, wheat, poultry, beef, sugar and cooking oil among other consumer goods as pointed out by Bloch (2010, 2011). As food insecurity is inextricably intertwined with the overall health of a person, as such it affects the balance of the quality of the health equation.

This view is shared by Hanke (2008) who tracked the root cause of hyperinflation in Zimbabwe during this period to the centralised state policies which forced the central bank to print money. In addition, the Central Bank became involved in quasi-fiscal activities such as procurement and sourcing of health commodities, agricultural inputs fuel and raw materials. It affected capital (k) formation which with labour (l) is the key input source of growth and development according to Thirlwill (2005). This assertion is vindicated by studies by the World Bank (1991), Shaaeldin (1989), Young (1995) and Senhadji (2000) which show the preponderance of capital and then labour as factors of production necessary for growth and they cite the East and South East Asian countries.

The decade 1998-2008 accelerated the decline in health delivery due to the economic crisis. Health service delivery suffered due to lack of investment in health delivery facilities and commodities. From

⁵ The reserve had sub contracted a printing firm in Germany to print the new currency; later it could only import ink.

⁶ The currency held in a country that includes deposits and currency held by commercial and building societies.

⁷ The currency supplied in a country that includes all deposits held by banks and building societies.

the literature⁸, the following structural causes of the economic crisis can be attributed to the failure of the post white settler colonial state, the contestable land reform/invasions, the participation of the country in the Democratic Republic of Congo (DRC) civil war and the awarding of bonuses to liberation war veterans. According to Kanyenze and Kondo (2011), Raftopoulos and Mlambo (2009), Meredith (2007) and Chung (2005), all of the above combined to precipitate the inflationary conditions and subsequent economic meltdown. For example, the land reform/ invasions are often cited as a failure by the state to uphold the rule of law and property rights as Richardson (2005) notes. This, according to Hanke (2008), Chung (2005) and Bloch (2010) contributed to capital flight, crisis of accumulation and total factor productivity in Zimbabwe. The effects on the health delivery which remain pronounced to date included;

- 1 Erosion of salaries of health workers such that they could not afford to come to work. The lack of foreign currency affected the importation of health commodities and equipment coupled by the human resource flight as noted by the UNDP report (2008). For Human Immunodeficiency Virus (HIV) financing, hyperinflation eroded the value of the National AIDS levy and domestic sources that had contributed to significant levels of funding of national HIV and AIDS interventions including staff emoluments. By 2008, hyper-inflation had so severely decimated the value of the Zimbabwe dollar resulting in remittances to the National AIDS Trust Fund (NATF) to shrink considerably from USD28 million in 2001 to USD348,349 in 2008 National AIDS Council (NAC, 2009).
- 2 The closure of many companies was due to low productive capacity which affected the recurrent and current budget expenditure according to Robertson (2007). This contributed to the deindustrialisation and crowding out of the pharmaceutical companies that had the capacity to produce and supply Anti-retroviral Drugs (ARVs), as the country became dependent on development partners for support towards health commodity procurement and supply.
- 3 As a result of the above challenges, the state conceded that the health delivery system nearly collapsed as stated in the Health Investment case document (2010:4) which noted that “*the health system, which is supposed to assist in improving these indicators, has almost collapsed*”. The erosion of Zimbabwe’s health system is indexed by a fall in key health indicators. Between 1990 and 2008, life expectancy at birth fell from 62 to 44 years (World Bank, 2010). The above have contributed towards household dissatisfaction with health delivery mostly in public health

⁸ Sachikonye, L. (2012). Zimbabwe's Lost Decade. Politics, Development and Society. Harare; Weaver Press. Kanyenze, G. and Kondo, T. (2011). Beyond the Enclave. Towards a Pro-Poor and Inclusive Development Strategy for Zimbabwe. Harare: Weaver Press. Raftopolous, B. And Mambo, B. (eds) (2009). Becoming Zimbabwe a History from pre-colonial period to 2008. Hammer, A. And Raftopolous, B. (eds). (2003). Zimbabwe unfinished business: rethinking land, state and nation in the context of crisis. Harare; Weaver Press. Bond, P. And Manyanya, M. (2003). Zimbabwe’s Plunge: Exhausted nationalism, neoliberalism, and the search for social justice. Harare: weaver press.

facilities as reported in the studies on *Access to Health Care Services in Zimbabwe* (2008) and *the Assessment of Primary Health Care in Zimbabwe* (2010).

After 2009 and beyond is a period of trying to address the near systemic collapse of the health delivery system in Zimbabwe. However immense challenges remain and continue to impact negatively on the health delivery system. The National Health Strategy 2009-2013 (MOHCW, 2009) noted that equipment is old, obsolete and non-functional, as a result of both lack of regular maintenance and replacement.

2.2. Current state of health delivery system

The purpose of this section is to describe the health system in Zimbabwe according to the health delivery structures, financing arrangements; quality of care and a review of related literature is provided. In addition, the role of the private health sector is also briefly discussed. The reason for undertaking this approach is based firstly on the assumption that these components of the health delivery system influence the treatment seeking behaviour of PLWH on ART. Secondly the treatment seeking behaviours and decisions made on choices of spending more have a dialectical relationship to out of pocket payments and of coping strategies which lead to impoverishment through asset depletion and or food insecurity and poverty in general among PLWH. As will be seen and discussed according to the conceptual framework based on the work of Russell (2004) in chapter three below.

2.2.1. Delivery structures

The Ministry of health and child care (MoHCC) is responsible for the overall health investment, allocation, surveillance, monitoring and evaluation at national level. It is also responsible for the nation's public health system including infrastructure such as all provincial and district hospitals, the staff and resources that are required to make these facilities operational. These tertiary health care institutions include provincial hospitals one each for the 10 provinces excluding Harare and Bulawayo which have central hospitals that are able to act as referral centres. Funding is based on the annual budget allocation from the ministry of finance. The local authorities are responsible for building and managing some of the health facilities such as hospitals and clinics. Funding is normally through levies (rates), government grants, development partners and from the local households through user fees. Not for profit health facilities such as mission hospitals are run and administered by various church related organisations which also offer a variety of health services including ART.

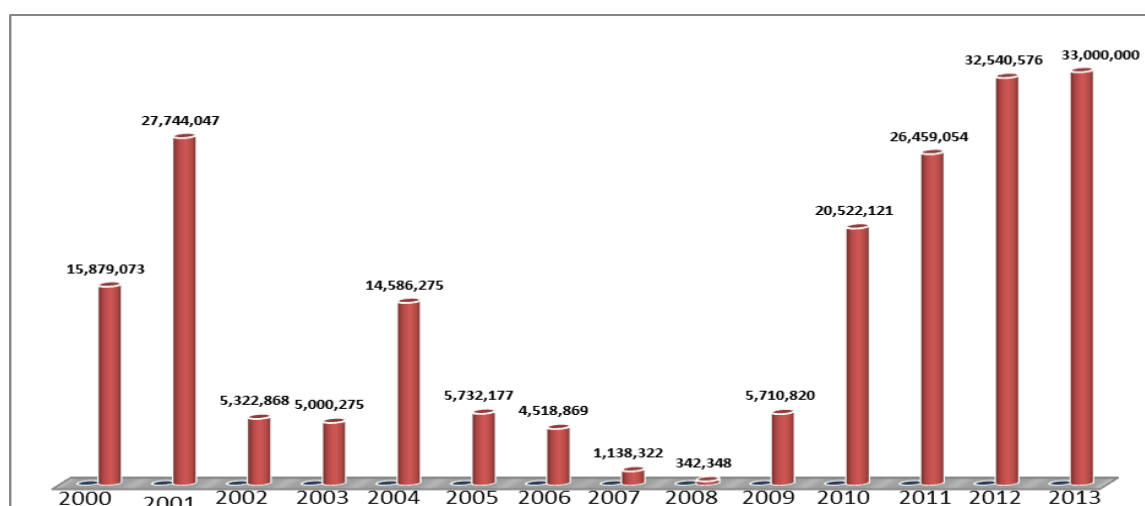
2.2.2. Health financing mechanisms including user fees

The health financing mechanisms have a tremendous influence in the way treatment seeking behaviour patterns develop and the occurrence of OPPs. The nature of who and how payment is made determines the type of health service sought for. In this section, an over view of the health financing

mechanisms are provided. In Zimbabwe, the following four broad categories define the financing mechanisms for Health and HIV in particular:

1. Payroll based tax (AIDS levy). This a special tax introduced in 2000 to mobilise additional domestic sustainable resources for the national response. Over the years this source of funding whose value is shown below has continued to play a critical role mostly in the procurement of ARVs, normally supplied through public health facilities. The AIDS levy is based on a 3% levy on all individual and corporate income paid monthly and is collected through the Zimbabwe Revenue Authority (ZIMRA) and disbursed through the National AIDS Trust Fund (NATF), which is managed by the National AIDS Council (NAC). The NATF is the main source of MoHCC funding to purchase ARVs according to the MoHCC (2008:184).

Figure 1: AIDS levy receipt 2000-2013 in USD



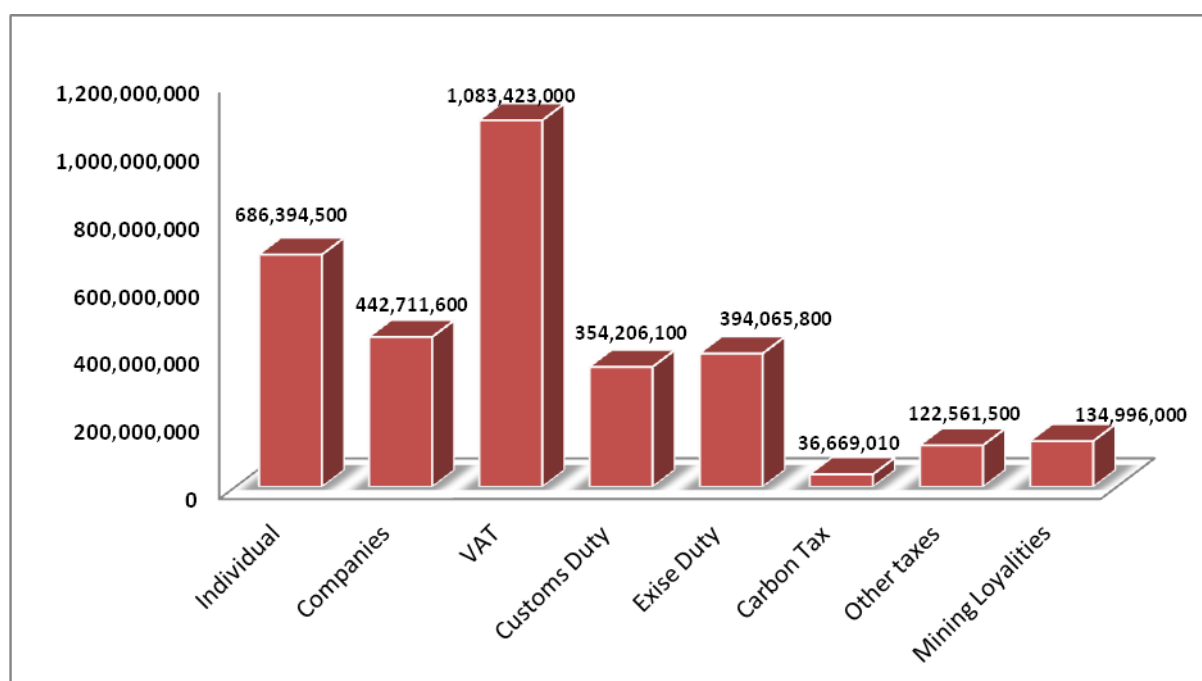
Source: NAC Annual reports 2000-2013

Funding from International partners continues to be equally significant with the bulk of health and HIV financing whose main sources are the Global Fund; Presidential Emergency Plan for AIDS Relief (PEPFAR), UN agencies and other bilateral sources⁹. For example, the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) under the new funding model, GFATM awarded Zimbabwe US\$311 for the period 2014 to 2016. This helps to show the magnitude of support emanating from various development partners to the HIV and AID response.

⁹ Interviews with representatives including the 1st Secretary European Commission (EC), United Nations Fund for Population Activities (UNFPA), 2nd secretary Swedish International Development Agency (SIDA), Health advisor Department for International Development (DFID), HIV advisors from World Health Organisation (WHO) (October and November 2011) in Harare.

2. The National Budget allocation through the vote allocated to the Ministry of Health and Child welfare is mostly used for recurrent expenditure (infrastructure maintenance and administrative over expenditures for staff salaries and utilities). Some Ministry departments have also received a supplementary vote for HIV related activities mostly used for preventive interventions and health promotion. It needs to be borne in mind that households also contribute significantly towards the national health budget through various taxes regressive (i.e. user fees and other forms of OPPs) and progressive as illustrated in figure 2 below.

Figure 2: Sources of fiscal revenue 2012



Source: Statement by the ZIMRA board chairman on revenue performance for the year ended 31 December 2012

Rates and levies help to support recurrent expenditure associated with primary health and secondary health facilities administered by the local authorities. To complement the local taxes, user fees are charged. According to the health care service study (2008) done in Zimbabwe, the majority of communities from the urban, mining and commercial farming areas paid to access health through user fees. User fees were not introduced in the 1990s as some reports erroneously state (Johnson, 1998). Rather, they were introduced in 1985 but enforced more vigorously in 1991. This was part of the conditions the state acceded to as part of its request of balance of payment support

through the introduction of Structural Adjustment Programme¹⁰. User fees have become a form of rent, from which public health facilities collect towards paying the operational costs except salaries. This is also a result of decades of under investment in the health sector by the state due to the following; the lopsided implementation of the Structural Adjustment Programme which gave this an impetus and the economic decline from 2000 which exacerbated health service delivery failure. According to Russell and Gilson (1997) it was this laxity in enforcing user fees which can be credited to the Zimbabwe's government's phenomenal expansion of the health sector in the first decade of independence. In 2002, a user fee policy¹¹ was promulgated, which exempted maternity, TB, HIV, epidemic conditions, those under five and pensioners from paying. However, the lack of capacity to enforce this has seen various fees being levied dependent on type of service sought.

The decline in ability by the state to provide adequate funding towards local area or municipality run health facilities such as poly clinics and hospitals, has made local authorities dependent on development partners and households through user fees as Mungofa¹² points out, that;

The ICRC currently provides 75 percent of City Health services polyclinics drugs needs, while the remaining 25% comes from other donors through the National Pharmaceutical Company and City health services own drug purchases. The value of ICRC drug supplies, equipment and other support is estimated at US\$866 000 in 2010. He further states that;

The contribution of the central government has been on the decline for the past 15 years right now the grant received from the ministry of Health and Child Welfare constitutes less than one percent of the total annual city health expenditures.

The Zimbabwe Health Assessment Report (2010:33) noted that patients were usually not cognisant of user fee changes until the moment of accessing the service. Field visits by the

¹⁰ Bijlmaier et al (1998). Provide the socio economic effects of the introduction of user fees including the challenges faced in implementing these fees.

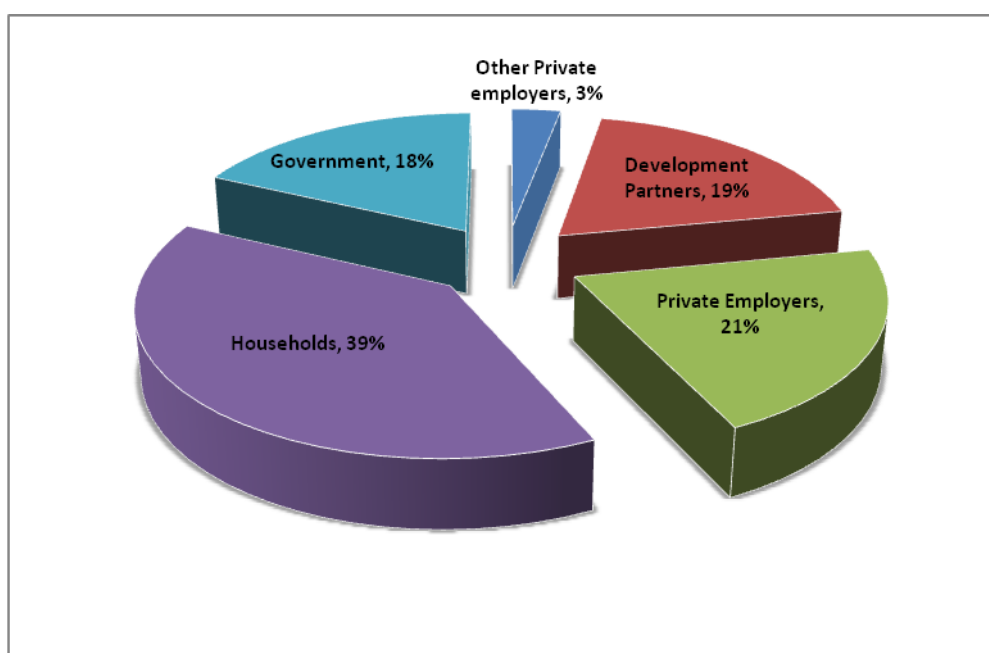
¹¹ The comprehensive user fee policy for public health facilities was introduced in January 2002. This policy includes: No fees to be charged at Government RCH, and RDC clinics, no fees to be charged for maternity services, free health services for children under-5, HIV, free TB treatment in public and private sector, and free treatment for pensioners.

¹² Interview with Director of City Health, Harare City, Dr. Stanley Mungofa carried in article "Council in Crisis as major donor pulls out" in Sunday Mail 16-22, 2012 "An evaluation of health financing policies and strategies for Harare City health services".

Expanded Support Programme Zimbabwe Second Annual Independent Review Team (2009:26) revealed that fees charged vary from one facility to another. In addition, while some facilities only charge HIV patients an initial consultation fee, others charge a fee for every visit; some PLWH reported that this prevented them from collecting their ARVs. Also, the payment for necessary tests and opportunistic infections (OI) related medications by patients at some facilities (including tests such as chest x-ray, CD4, CD8 and liver function) were an obstacle to treatment. Other costs including medication to counter the effects of side effects associated with taking the medication, as well as for supplementary food, also impinge on patients' capacity to continue with ART.

3. Private contributions were sought through (a) formal co-payment and (b) fee for a service, which is where out of pocket, is largely located and is manifested through co-payment, user or consultation fees. The contribution and significance of households towards health financing, if put in context of other funding modalities is illustrated figure 3 below;

Figure 3: Health funding sources



Source: National health accounts of 2010 (MoHCC, 2013)

According to National AIDS Council 2012 annual report (2013:30), the cost per person per year of being on ART in the public sector was USD72, while in the private sector it was USD240.

2.2.3. Quality of care

In recent years, there has been growing concern in many countries that the public health programmes have placed insufficient emphasis on the quality of their services as Ickis (1992); Mensch (1993); Miller et al (1991) point out. Basing their observation on a study of the Indonesian health system, Sarah et al (1997) have stated that the quality of health care delivery depends on the availability, type,

and number of health workers. This definition is rather reductionist in the sense that it excludes other critical components of the health system required to provide quality of health services such as health funding and constant availability and supply of prophylaxis. Jain (1989) defines quality health care in terms of the way individuals and clients are treated by service provision systems. Quality health care may imply either meeting the minimal standards for adequate health care or offering the greatest benefits, with the least health risks, to the greatest number of people given the available resources (Huber 1994). This definition calls for an understanding of health needs that go beyond a reductionist biomedical to a more multidimensional approach. Such an approach explores the relationship between various ecosystems, components which include economic, political, biophysical and socio-cultural and how they shape priority determinants of health and well-being. Quality improvement of services related to HIV and AIDS in this regard is defined by WHO (2004) as:

The process of improving adherence to standard guidelines; improving the structure, process and outcome of HIV and AIDS response and meeting the needs of patients/clients in a culturally acceptable way.



Trained and motivated nurses are a pre-requisite for any health delivery system: Picture by John Cassim

From a health care provider's perspective, structural improvements and the processes which culminate from them imply examining the quality of human resources in terms of adequacy in terms of quantity and quality of care. By quality care it is implied clinical care offered in a technically competent, effective and safe ways that contribute to an individual's well-being (Brown et al 1995).

Mary et al (1998) make the observation that, due to the macroeconomic challenges that followed the period of the Economic Structural Adjustment Programme (SAP)¹³, community women began to perceive nurses as hardened and indifferent, especially in urban areas. These differences are rooted in the perceived class differences between nurses and the communities they serve. Thus, the major challenge facing health care professionals in this situation is whether professionalism can be reinvented to include performance-based competency and scientifically driven quality improvement.

Mindful of the observation made by Batalden and Davidoff (2007), medicine is an enormous and highly specialized body of knowledge makes it a learned profession, but delivering care is performance, not scholarship. In this vein, Landon et al (2003) extends the above argument by advocating for specialist training for physicians offering treatment to HIV patients as a possible route to take in order to achieve the goal of quality of care. This is based on the findings of the study undertaken by Landon et al (2003) that analysed 1,820 patients being cared for by 374 physicians to assess the association of specialty training and experience in the care of HIV disease with the adoption and use of highly active antiretroviral (ARV) therapy (HAART). According to their findings, it was demonstrated that expert generalists who develop specialized expertise are able to provide care of quality comparable to that of specialists. Patients treated by non-expert generalists were less likely to be on appropriate ARV therapy. In addition to training, for a provider to offer quality health care, there is further need to recognize the importance of support services such as logistics, infrastructure, availability of functional and reliable equipment and record keeping.

Policy makers and development partners, on the other hand, look at cost, efficiency and outcomes of the population as the additional key elements of quality. Putting clients first is the key to improving the quality of health services. It should be noted that clients are experts on their own personal needs as argued by Morgan and Murgatroyd (1994). Thus, from a client's perspective, quality of care is inclusive of their interaction with service providers involving factors such as waiting time, ease of access and whether or not they eventually get the services they want.

¹³ The Structural Adjustment Programme has been blamed for having led to the depreciation of real income of the working population, several scholars in particular Mwanza (1999) has provided a detailed study on the ramification of the structural adjustment on the quality of Healthcare delivery system in Zimbabwe.

The quality of healthcare is not clearly defined beyond observable facility characteristics such as the availability of medicines and functional equipment as pointed out by Collier (2003), Dercon and MacKinnon (2003); Lavy and Germain (1994). The view is shared by Manangazira¹⁴ who, says;

We are a service industry which has to provide the necessary quantity and quality of services through the provision of sufficient human, equipment and necessary prophylaxis required for the prevention, treatment and care of those in need of better health.

The shortage of Cotrimoxazole was noted by respondents in the study by Kanhira et al (2010) as a barrier to access treatment. In the context of Zimbabwe, the Expanded Support Programme Zimbabwe Second Annual Independent Review Report April (2009:25) reported stock outs of commodities such as Cotrimoxazole and other essential drugs, and the unavailability of laboratory staff to operate CD4 machines in some districts. The National AIDS Council Annual Report (2012:31) noted shortages of drugs, which were experienced during 2012, with Tenofovir, Zidovudine-N, Coviro, Stalanev, Tenolam, Lepinavir and Triomune-baby cited as being the ones that ran out of stock (stock outs). The report attributes the disruptions to poor ordering and stock management by health care workers. This results in demand for services and commodities being transferred to other facilities thereby resulting in OPPs as patients seek health services from a secondary provider instead of receiving this from their first provider.

In concluding this section, it can be argued that the quality of health care can only be as efficacious as the sum total of its components which include health services (staff, equipment, facilities among others) and health commodities (including ARVs, auxiliary antibiotics and therapeutic micronutrient supplementation). What is less well understood, but has greater relevance for both the use and outcomes of services, is the quality of actual advice given in clinical settings. Medicines can be bought over the counter. Nevertheless, good advice from a provider with knowledge and experience is a service that patients cannot obtain by themselves. Many studies on the demand for medical services identify quality as a major determinant of facility selection and use. As a result of treatment seeking behaviour and the difficult choice a patient makes in pursuit of better health services or care, OPPs are incurred, which may negatively impact on household livelihoods. The next section on the extent of the private sector will describe and show how the growth of this sector has been due to the difficult choices patients make to seek treatment or no treatment at all. The private sector provides services and supply drugs that may not be readily available in the required quantity and quality in public health

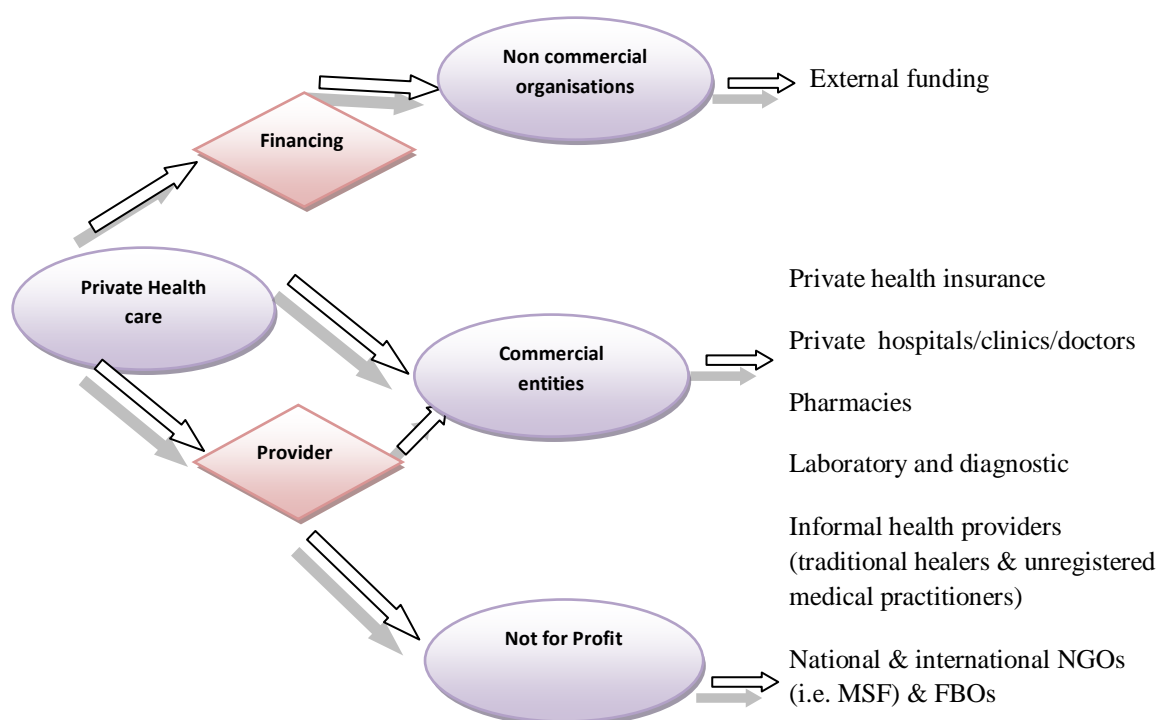
¹⁴Interview held with Dr. Portia Manangazira Director of Epidemiology and Disease Control, Ministry of Health and Child Care on 18th August 2011.

facilities. As a result patients end up going to private health providers as they are guaranteed of both services and prophylaxis although at higher costs.

2.2.4 Extent of private health providers

In this section, the extent and role of the private health sector is discussed as this sector has immense consequences for treatment through direct costs/OPPs in total or as co-payments for the few who happen to have medical insurance. Its growth under seemingly difficult conditions and structure are discussed below. Bennett and Ngalande-Banda (1994), Hanson and Berman (1994) define private health service providers to be composed of those providing health related services outside the ambit of the state. Foster (2012:7) goes further to graphically represent the private sector to include the funding source as indicated below:

Figure 4: Structure of private health service providers in Zimbabwe



The slowdown of the economy in the 1990's saw a decline in savings and investment, which affected the social sector more specifically health, as growing budget deficit grew and a marked increase in unemployment arose. The need for balance of payment support, from the international multilateral institutions such as the World Bank and IMF made the country to accede to economic reforms. These reforms compelled the country to cut down on social investment and accelerate the enforcement of user fees. This situation was further worsened by the economic crisis of 2000-2008 in which the health sector almost collapsed as MoHCC (2012) and Osika et al (2011) detail. As described in the

political economic context above, health service delivery was greatly affected. This saw drastic market failure by the post white settler state in health delivery, as a consequence most public health facilities either closed due to lack of the human resources, capital investments and availability of prophylaxis. This resulted in a general scepticism and lack of trust of this sector by the population who increasingly sought health care from the private sector. As Minister of Health and Child Care (2014)¹⁵ noted “*These private clinics and pharmacies you see sprouting about and competing for space are a result of the gap in the provision of services created by the government*”. He further laments that (2014)¹⁶:

Nearly half of the posts for specialist medical personnel in public health institutions are vacant owing to the Government’s failure to offer attractive conditions of service. With only 7 specialist doctors at major referral hospitals out of the required post establishment of 26...There were only 4 specialists instead of 140 at provincial hospitals¹⁷. Currently we have one pathologist serving the entire country. What is needed is a meaningful investment in the health sector, enough to lure skilled and experienced personnel....

In economic theory, the law of supply and demand necessitates the creation of markets which can be exploited. These factors gave impetus to the private health sector which further consolidated horizontal linkages between the medical practitioners, private clinics and laboratories. These horizontal linkages not only crowded out competition, but due to monopolistic tendencies, they also increased the cost of health care provision. The growth of this sector benefited from various legal instruments namely the Medical Service Act (1998) which has no further legal supporting framework, the Traditional Medical Practitioners Act (1981)(Chapter 27:14) and Natural Therapist Act of (1981). However, these regulatory instruments have tended to focus more on entry requirements in to the sector. Except for the Traditional Medical Practitioners Act (1981), there has not been a deliberate attempt to enforce these legal instruments especially Medical Service Act (1998). In a study by Lewis (2006), it was found out that general shortage of drugs discourages uptake of medical services. This can be due to poor remuneration paid to health personnel for services resulting in them referring patients’ to their private practices¹⁸. Furthermore, the lack of capacity by the Ministry of Health and

¹⁵ Interview with Minister of Health and Child Care, Harare, In the Herald of 21st October 2013.

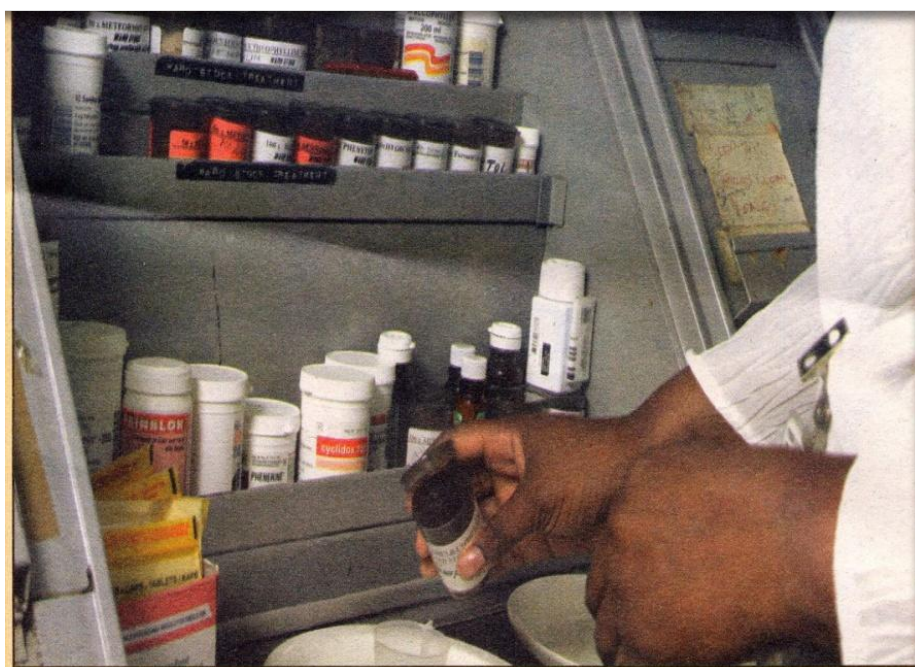
¹⁶ Ibid.

¹⁷ A Provincial hospital is supposed to be the main referral hospital catering for districts in a province.

¹⁸ A Harare nurse said low wages had sometimes led to staff accepting bribes from patients for quicker treatment and hospital admission, and selling ARVs that were available for free to HIV-positive people. "The government is paying health staff peanuts and as a result workers dedicate their time to moonlighting, are usually absent from their workstations, and tend to give flimsy excuses to be away from work," said Japhet Moyo, deputy secretary general of the Zimbabwe Congress of Trade Unions (ZCTU) to IRIN, [3/12/2010 - www.irines.org]

Child Care to effectively regulate fees and charges in the private health sector, has given latitude to this sector to peg their fees as they wish¹⁹.

The failure by the state to pay for the local pharmaceuticals and the liberalisation of this sector has also meant that local pharmaceuticals are crowded out by development partners who have established their own procurement and supply procedures to meet the demand of NGOs they support. It needs to be pointed out that public or government hospitals rely mainly on pharmaceuticals from local manufactures but the inability by the government to pay on time has resulted in either stocks not being replenished or provided at all in public health facilities. The current drug levels in public hospitals range between 29% and 58% for vital drugs against a target of 100%, and between 22% and 36 % for all categories on the essential drugs list against a target of between 75% and 80%, according to the MOF (2011:45).



Pharmacist dispensing medication: Photo by Shadreck Pongo

Pharmaceuticals from India demand foreign currency payment up front, which the government has not been able to provide consistently. Yet, private health providers have been able to buy both locally and import the necessary pharmaceuticals. This section has briefly described the growth in private providers of service such as pharmacies and hospital/clinics. It has been done with the hope of

¹⁹ Towards the end of 2010 the Ministry of Health began to make moves to introduce regulations that were agreed in 2000 but were abandoned during the economic recession. The Minister (now former) of Health and Child Care, Henry Madzorera said, "Now that we are over the turbulent economic period, we have every intention of enforcing the regulations governing your industry. We are not making any new laws or regulations as of now. Let us first implement what is in place already," [*Financial Gazette* 07 October 2010]

explaining the failure of the post white settler colonial state to provide the required quantity of pharmaceuticals and human resources.

Shortages of essential prophylaxis, poorly motivated health personnel and long waiting queues have contributed to a thriving private health sector comprising of hospitals, clinics and pharmaceuticals as patients who first seek medical attention from the public health facilities end up accessing services and commodities in this sector. It is no wonder that, according to PICES (2011/12:79) 50.5% of the poor used public health facilities, compared to 43.7% non-poor who went to such facilities for treatment. Given the payment modalities which are cash, OPPs tend to be very high which affect household budgets and have the propensity to cause impoverishment.

The next section provides an overview of the status of health insurance. The rationale is to connect the ability to pay for treatment choices or treatment at all to the availability of health insurance. Health insurance can help smooth consumption and reduce incidence of OPPs.

2.2.5 Health insurance coverage

While there are no official statistics on the number of people in the informal sector, it is estimated that they constitute about 80 percent of the population. As the Zimbabwe Health Assessment Report (2010:16) noted less than 1% of the population had health insurance in Zimbabwe. According to the Zimbabwe Demographic Health Survey (2012:41) the number of women who did not have insurance coverage was 93% while for men it was 91%. In Harare, it was 86.5% of women and 84.7% for men who did not have health insurance. The lack of adequate funds from both the government and development partners has in part affected its coverage. For health, a National Health Insurance Scheme was suspended in 2007 due to macro-economic challenges from 2000 to 2009 when Zimbabwe experienced a fiscal crisis and decline in economic activity in all sectors of the economy. Hyperinflation, company closures and unemployment all made resource mobilisation difficult for the government, let alone for the health sector. One of the specific health insurance initiatives the Ministry of Labour and Social Services operates is through the Assisted Medical Payment Treatment Orders (AMPTO).

In terms of social protection, various mechanisms are in place to mitigate the impact of the macro-economic environment. One of the major social mitigatory funding mechanisms has been through the Basic Education Assistance Module (BEAM) which is a demand side response to the cost barriers affecting the ability of orphans and vulnerable children (OVC) access education. The country has an estimated 1.6 million children made vulnerable by the HIV and AIDS epidemic, of these 5000 (0.3 percent) are living in institutions while the rest are being cared and supported by their families and communities (Ministry of Labour and Social Services (2010).

2.3 Conclusion

This chapter has provided an overview of the political economy of the country with the prime purpose of locating the health delivery system in it. The purpose is to provide a contextual overview that will help inform the reader of the conditions that give rise to out of pocket payments. Therefore, out of pocket payments are influenced by treatment seeking behaviour and decisions that motivate PLWH to spend more to access better health or care at all. The current funding mechanisms based on internal initiatives such as the National AIDS levy and external sources of health finance from the global fund have been discussed. The section also provided an analysis of the quality of health and the rise and growth of the private health sector with greater emphasis being placed on the pharmaceutical sector due to its importance in the supply chain of commodities. The chapter will help inform the findings and help to better understand why difficult decisions on choice of services are made and how treatment seeking behaviour that sometimes leads to out of pocket payments arises due to the need to buy commodities privately as a result of market failure. This has seen the negation of the provision of health as a public good that the state has a mandatory obligation to ensure that it is delivered in sufficient quantity and quality. The health system background has been discussed in relation to the literature and more importantly to Zimbabwe as it has a major bearing on treatment seeking behaviours that arise and out of pocket payments that tend to develop.

Chapter Three: Literature review

3.1 Introduction

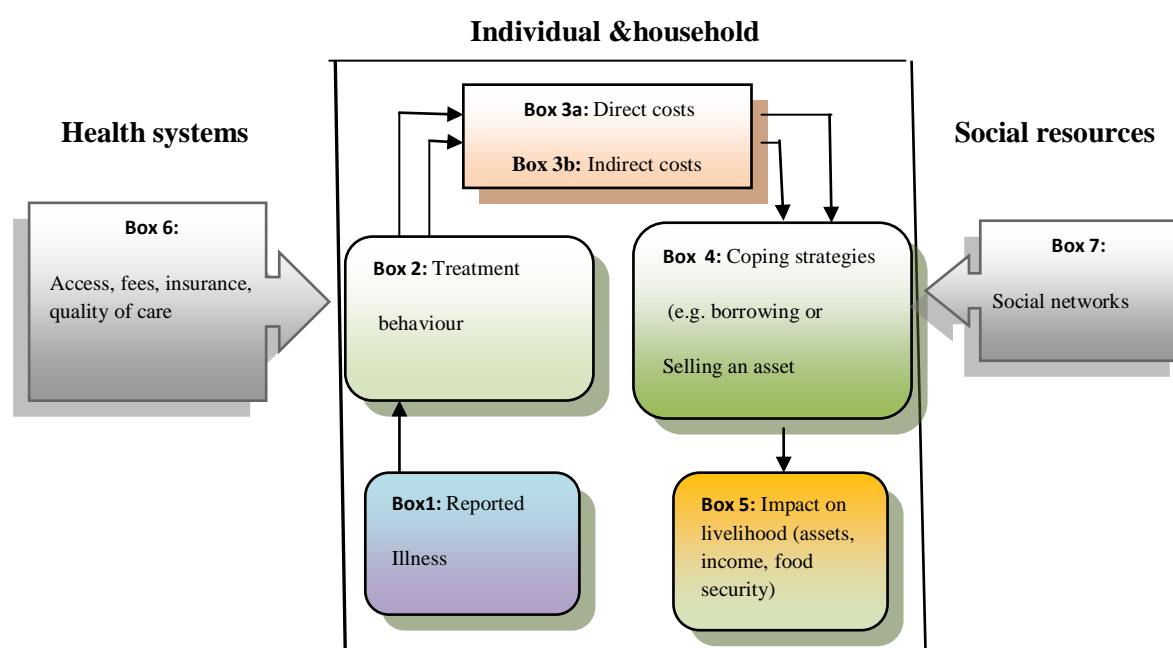
The purpose of this chapter is to provide a conceptual framework that can articulate the cost of illness and treatment seeking behaviour by PLWH and the effects this has on their social reproduction of individuals and households. More specifically, the Chapter seeks to provide a framework on which the key concepts and variables for the research will be undertaken regarding the health systems and treatment seeking behaviour that result in direct costs such as out of pocket payments by PLWH in Harare Metropolitan Province (HMP). The socio-cultural factors identified by Kagee et al, (2011) which influence treatment seeking behaviour will be used to complement the direct cost factors identified by Russell (2004) as contributing towards the economic burden of illness. Although some of the literature included is bio-medical and is interwoven with the key variables that will be measured, the purpose is to show the health consequences when direct costs affect affordability of treatment. Treatment choices and the cost of treatment can impact on households and this result in coping strategies being triggered to mitigate costs. In some instances resilient mechanisms fail resulting in increased impoverishment of households.

3.2 Conceptual framework for treatment seeking behaviour and economic costs of illness

The treatment seeking behaviour and economic burden of illness in terms of costs, coping strategies and consequences on households is informed largely by the conceptual framework by Russell (2004). According to this analytical framework illustrated below, health systems, which comprise access, user fees, health insurance and quality of health, determine treatment seeking behaviour. This treatment seeking behaviour results in direct and indirect costs which could also be attributable to the health system. As a result of these direct costs due to health shocks, households adopt various coping mechanisms that include the borrowing and selling of assets. Consequently, households' livelihoods are impacted in terms of asset depletion and food insecurity due to lack of a source of sustainable income. McIntyre et al (2006) provide an elaborate model which could have been appropriate in this study especially if the indirect costs were to be the focus and how they influence treatment seeking behaviour resulting in coping strategies and impact on households. This study focuses on the direct costs caused by treatment seeking behaviour and treatment choices only in relation to their impact on average household income, the coping strategies and the effects they have. In addition, a sub-analytical framework is used to explain better the role of socio-cultural factors such as stigma and religion in influencing some of the treatment seeking behaviour, based on the work of Kagee et al (2011). The rationale for this is that the treatment seeking behaviour is not conditioned by economic/financial conditions only but socio-cultural factors also play a significant role in the choices people make in terms of treatment seeking behaviour.

In adopting the conceptual framework by Russell (2004), consideration of other analytical frameworks such as McIntyre et al (2005), Ir et al (2012), Alam and Mahal (2014) was undertaken. Despite being more elaborate, the schematic model by McIntyre et al (2006) has the following inherent limitations. The model does not show the significance of health systems whose attributes such as access, user fees, health insurance and quality of care are key determinants of direct and indirect costs of treatment seeking behaviour. These are used in this study as the basis upon which they will provide the criteria to measure how the direct cost of treatment seeking behaviour arises. The other issue which is not clear in the McIntyre et al (2006) model is the meaning of medical poverty trap; Is it ill-health caused by poverty? To reduce direct and indirect costs of treatment to just a medical poverty condition strips poverty of its multidimensional nature. There are variations such as the impact that arises from poverty and the impact it causes such as borrowing and asset depletion. The conceptual framework proposed by Alam and Mahal (2014:3) and Ir et al (2012) do not locate health shock within the health system. Furthermore, another conceptual weakness in the conceptual model by Alam and Mahal (2014) is that it does not provide the cost categories which are necessary to translate to the economic burden of illness, which this researcher is interested in. As a result other key variables such as accessibility to treatment, fees, insurance and quality of care which have a bearing on direct and indirect costs and can be a cause for catastrophic consequences are not included. These limitations are profound as Navarro (1976) points out, ill-health cannot be viewed in isolation of its social and political economic context. The conceptual framework with emphasis on direct costs is outlined below, in relation to the health system discussed in the chapter two.

Figure 5: Conceptual framework for analysing the economic burden of illness



Source: Adopted from Russell (2004:148)

There are several direct costs due to illness that affect PLWH in accessing health. These can be attributed to treatment seeking behaviour, lack of health insurance, self-treatment or over the counter purchases, transport and diagnostic tests. These direct cost categories are what the researcher in this study will seek to measure, describe and explain. The study provides details of the consequences that bring about the need to borrow and or sell an asset due to ill health. In addition, the researcher describes and explains the impact of out of pocket expenses towards impoverishment and food insecurity caused by treatment seeking behavior and direct costs/OPPs in chapter five on the findings and chapter six in the discussion of the results..

3.2.1 Treatment seeking behaviour

Socio-Psychological and behavioural factors play an important role in shaping treatment seeking behaviour which results in out of pocket payments. Stigma and traditional beliefs are an important factor with regards to health-seeking behaviour. While the literature below notes that direct costs of illness can be a result of direct cost of accessing treatment caused by health system failure, treatment seeking behaviour can contribute to these costs. Treatment seeking behaviour is influenced by socio-cultural factors alluded to by Kagee et al (2011). Cultural factors include stigma and belief systems and these can be added institutional factors (waiting time and drug stock outs). Some individual patients shy away from public hospitals owing to the need not to be seen to be taking antiretroviral medication. The patients therefore seek treatment at other health facilities which might be at a higher cost preferably a private pharmacy or a clinic out of the patient's community. These direct costs can be in the form of transport and or paying for medication.

3.2.1.1 Stigma

Cultural barriers to early HIV testing and treatment include stigma and beliefs about HIV and AIDS as noted by Kagee et al (2011), Deacon (2009), Steinberg (2008), Obermeyer and Osbone (2007). What these studies highlight is the fact that one of the main barriers to HIV testing is the fear of – or actual - stigma. The Zimbabwe HIV and AIDS Union Community Trust (ZHAAUCT, 2013) notes that, at a personal level, PLWH are afraid of being seen by other members of their family, friends and neighbours in a queue for ART, or in some cases the opportunistic infections (OI) facility is made conspicuous by its location. Patients resort to seeking services away from their nearest health facility and in the process; they incur direct costs due to transport or the need to buy medicine away from their known community. Kanhira et al (2010:123) noted from their study that 67% of PLWH fear being seen at the clinic in their community. As a result they often go to other health centres where there status was not known to access ARVs. This results in either direct costs (transport) or indirect cost in the form of lost productive labour time. The indirect costs may also be incurred if they have to pay for the caregiver as Russell (2004) and McIntyre (2006) have noted in their analytical frameworks.



HIV voluntarily counselling and testing queue at a mobile site in Harare: Photo by Grace Chikodzi

While the picture above may show a long queue during one of the campaigns on HIV counselling and testing, the queue for collecting the results will not be as long. This is because; friends and neighbours would be inquisitive to know the status of the tested person. The fear of a male partner, family and other (employees, neighbours) reactions influenced stigma at a personal level according to Weiser et al (2006). Nyblade et al (2009) note from their qualitative study done in Kenya, that fear of being tested for HIV made delivery of infants at home or using traditional birth attendants more attractive. HIV testing would involve having to disclose a person's status to their partner. Turin et al (2008) believe that health workers also contribute towards HIV stigmatisation by their discriminatory approach towards patients with HIV which might motivate PLWH to seek treatment from the first provider to a subsequent one thereby incurring higher costs. Family structures that include the household income capacity and social support are essential for adherence to ART (Holstad, et. al, 2006). Holstad et al (2006) further point out that living conditions in communities in developing countries tend to be characterised by lack of amenities, as well as overcrowding and lack of privacy. This is not only symptomatic of poverty which creates these situations but provides the environment which influences people in the way they behave as Hickel (2012), Bandura (1997) and Hogben and Byrne (1998) indicate. This then forces people to either seek services away from where they are known to other providers of services who can ensure either confidentiality (private) or public providers at another place given the morality surrounding HIV²⁰.

²⁰ Recent reports in the media have highlighted this fact where STI including HIV treatment was being sought far from where the patients resided as a way to avoid gossip about ones condition as patients reported. (Harare News, Issue 31, April 2016).

Religion can be contradictory in the way it relates to PLWH or towards HIV in general. On one hand religion provides solace and at times material assistance to the bedridden or support during bereavement. Dilger (2007), Anderson et al (2009), Cotton et al (2006) and Pargament (2004) state that religion helps to cope with anxiety and depression often associated with HIV and AIDS. The extreme side of religion is experienced where prayer is thought to heal those with HIV and render ARVs unnecessary (Wanyama, 2007). What is important in Wanyama's (2007) observation is the averted direct cost of having to pay for treatment. Genrich et al (2004) argue that religion can be a source of perceived stigma through its structures, which make PLWH subconsciously or unconsciously believe they are being punished for behaving immorally. The discourse on religion and HIV has to be placed in the context of HIV being a sexual transmitted infection (STI) which then evokes moral judgement, resulting in congregants believing that HIV can be contracted through sharing worship space as Nyblade et al. (2003) observed. Deribe et al (2008), Hutchinson et al (2007) and Medley et al. (2004) bring to the fore the idea of social withdrawal as patients avoid being shunned at public gatherings and religious spaces, because of the fear associated with stigma and the blame attached to HIV.

What the literature has not been able to provide, is the explanation that PLWH will resort to seeking treatment in private so as to be able to participate in the sharing of religious space without their health status being noticed. The need to seek treatment privately and confidentially has consequences as it results in direct costs/OPPs being incurred usually through treatment seeking behaviour that encourages private health services to be accessed more. It can be concluded that stigma will influence treatment seeking behaviour patterns by influencing congregants to access health services and commodities from private health providers.

3.2.1.2 Traditional beliefs

The use of traditional healers and medicines by PLWH in Southern Africa has been well documented by Babb et al (2007), Peltzer et al (2008) and Esther (2009). The use of traditional healers can be a coping mechanism and/or a source of direct cost depending on the motivation for seeking the services of a traditional healer. If the motive is to seek a cheap alternative to conventional treatment it becomes a coping strategy. If the motive is to get complimentary alternative medicine the services of the traditional healer become a direct cost to the patient in the sense that the patient will have to pay in cash or in kind. So the context in which services are sought will largely determine whether the services of a traditional healer are a coping strategy and or source of direct cost to the patient. De Smet et al (2002) and Rodriguez-Fragoso et al (2002) argue that there have been substantive benefits of traditional medicines. About 80% of low income countries still consult traditional health care practitioners, according to the World Health Organisation (2002). In a study by Kanhira et al (2010), it was established that 74.3% of HIV patients used traditional medicines instead or with ARVs. However, the reason for this treatment seeking behaviour is not given nor are the costs direct or

indirect implied in the study. As such, data would have been useful in estimating the impact of such treatment seeking behaviour on household capital accumulation, especially where livestock and/or cash have to be the form of payment.

Dahab et al (2008) interviewed 12 participants; six being patients on ART, five service providers and one human resource manager. In a qualitative study undertaken in South Africa on patient and provider perspectives on the barriers to and enablers of HIV treatment at workplace, the study found out that some of the patients consulted traditional healers to seek treatment for side effects associated with ARV treatment. A strength of this work is the way the authors, however briefly, weave in quotes from their key informant interviewees to support their findings. Being of geographic and methodological relevance, the study has limitations which need to be briefly highlighted here. Although there has been an extensive discussion of the individual factors and how they affect adherence, barriers such as disease treatment, health systems, patient/health care provider relationship do not receive sufficient coverage. Also pertinent is the perspective of the traditional healer with regards to the reasons why they are consulted by patients on ART. The rationale for interviewing the human resource manager is not provided, nor is the perspective of the human resources manager given in the study. Where the biomedical model fails to provide answers, as in the case of HIV and many aspects of it and its treatment, traditional beliefs in various cultural contexts assume relevance as noted by Pierret (2007). Mukonyora (1998:196) defines traditional healers popularly referred to as *N'angas* as:

Individuals who spend months living under water, in pools, rivers and oceans acquiring new skills and learning about medicine from njuzu a water spirit – mermaid.

Walker et al (2004), noted variables such as the inadequate health centres, the long waiting times, overcrowding and negotiable fees charged by practitioners who, in addition, tend to relate to the spiritual needs of patients as militating against service delivery for people on ART.

The above literature has focused on the therapeutic nature of complementary alternative medicine with little discussion on the effects this type of treatment seeking behaviour has on household livelihoods, savings and capital accumulation. The payment to traditional healers is a direct cost to the individual or household. Payment is in the form of money or livestock. Taylor (2001) justifies the role of traditional healers and medicines by locating his argument in the inability of supply side of health commodities such as pharmaceuticals to meet the needs of the majority of the poor in low and middle income countries. This observation is closest in the literature from which one can infer the link between treatment seeking behaviour and direct costs/OPPs that patients can incur.

3.2.1.3 Health systems/Institutional factors

In a study by Joglekaar et al (2011:957), long waiting time, delivery of service, doctor patient relations and fear of retribution from health providers were cited as factors that affected access to treatment. These have a domino effect on the demand of health services. The health institutional factors have a bearing on treatment seeking behaviour and the effects that give rise to further impoverishment.

3.2.1.3.1 Waiting time or opening hours

From a qualitative cohort study of 528 patients that defaulted treatment in a South African based study Miller et al (2010) note that one of the reasons cited by respondents was the long waiting time, which in turn would make them abandon treatment. The cause of delay according to the participants in the study was the number of patients waiting to be served and the amount of time spent on paper work. According to a study by Kunihiro et al (2010:125) health care systems barriers such as time spent to access treatment affected access to treatment by HIV patients.

According to their findings HIV patients spent a minimum of 7 hours or mean time of 8.36 hours waiting to access treatment. As a result 77.1% of the respondents cited this condition as one that would discourage patients from accessing treatment.



Patients waiting to be served in a queue at a clinic in Harare. Picture by John Cassim

According to Kunihiro et al (2010) this was a problem that was rooted in the shortage of health workers. Medecins Sans Frontieres (MSF) or doctors without borders (2007) noted that in Southern Africa inadequate infrastructure and staff shortages contributed towards long waiting times. McIntyre

and Thiede (2003) have shown that such long waiting time resulted in indirect costs to the patient in the form of labour substitution.

But this could also be a direct cost to the patient if they have to forgo wages due to the fact that the time spent in the queue could be used to put their labour to productive use. In some instances, the waiting time entailed buying food while waiting to access service as Russell (2004) and McIntyre et al (2006) point out in their respective analytical frameworks. In a study in Albania, Vian et al (2005) alluded to the fact that out of pocket payments in the form of informal payments from patients to health care providers was a way of soliciting better services and the need to speed up care. This corroborates with similar findings by Maestad and Mwisongo (2007) who found that gifts by patients were necessitated by the need to by-pass a queue or reduce the waiting times. In a qualitative study, Maestad and Mwisongo (2007) generate data on informal payments in health facilities, and how these affect the quality of care. Eight focus group discussions in four districts with fifty eight participants (n=58) who were health workers (doctors, clinical officers, nurses and medical assistants) were undertaken. The strength of the study by Maestad and Mwisongo (2007) lies in the fact that it shows the prevalence of direct costs that patients incur in the form of gifts of appreciation especially when a patient is helped to jump the queue. The practice of gifts of appreciation given to health workers for actual services rendered and bribes is obscure in whatever form, the gift of appreciation is a direct cost to the patient. The study also indicated that health workers were involved in rent seeking activities by creating artificial shortages and lowering the quality of health provision to patients who would have failed to pay. The weakness of the study is that only the supply side (health providers) are the basis of analysis and not the demand side (patients) who consume the health services and are affected by the gifts of appreciation. The argument for including patient perspectives would have been to show how gifts impact on livelihood and how the gifts result in impoverishment and food insecurity. This could have been possible if some quantification of the costs by patients was done or a description of the effects these gifts had on household social and economic reproductive capacity.

The ZHAAUCT (2014) notes that at some provincial hospitals in Zimbabwe, patients have to wake up as early as 4am if they are to queue in order to be attended to. The crisis of waking up early by patients was also due to inadequate staff at hospitals, and unfriendly opening and closing hours. This was socially disruptive and affected time available to be productive. Kagee et al (2011) cite the fear of patients being attacked by thieves in the process of having to be awake so early to access treatment. Other studies by Musheke et al (2013), Coetzee (2011), Hardon et al (2007) have also noted that waiting time can be a barrier to treatment as productive labour time is spent idle.

3.2.2 Direct costs of illness and the effects on health services

In the above schematic model on economic burden of illness, Russell (2004:148) provides two cost categories viz direct and indirect. The categories tend to be influenced by the type and severity of illness and the health system in place which determines the provision of health service according to choice of the patient. The health system in place will have a significant bearing on defining the type of cost to the patient. Direct cost pertains to those financial charges that relate to the household seeking treatment and include non-medical transactions such as transport costs. Indirect costs refer to those financial transactions that emanate from lost productive time due to individual or household being ill and for additional care provided through a care giver. McIntyre et al (2006) also distinguish cost categories between direct and indirect. Accordingly, direct costs are associated with payments that are for health services (consultation and diagnostic tests) and for treatment. Indirect costs are financial transactions incurred as a result of lost production time due to ill health or the need for labour substitution.

In a study that focuses on patients' costs of obtaining treatment for HIV/AIDS in South Africa, Rosen et. al. (2007) provides a useful category of direct costs to illness in terms of travel/transportation, clinic fees, purchase of special foods and other medications. In addition they provide indirect cost and categories for substitute labour, loss of income and care taker time. This is done to quantify the cost of patient expenses in seeking treatment in two South African provinces. However a key weakness in the study is that, it does not provide the cost for diagnostic tests such as Cluster Differentiation 4 (CD4 count), viral load and liver function tests which are normally a prerequisite for accessing ARVs. The non-inclusion of this category is not explained, as to whether diagnostic tests are part of the non-user fee charged for clinical visits. The selection of the sample was made from three different sites at health facilities where the questionnaires were administered by research assistants to patients during their routine visits. Data was collected by interviewers during the patient's routine visits. The advantages are that, the methods ensured a high response rate, and accuracy in completion of the questionnaire was sought through further clarification and additional information between the interviewer and the interviewees/patients. This method of data collection has its drawback as the study acknowledges that data on out of pocket costs spent on traditional healers was not provided. In spite of these limitations, the sample allows for a comparison of costs between urban and rural populations and cost variations between different service providers and among the communities served. The size of the random sample is big enough to ensure the study results can be generalised. For example, from a total population of 6200 patients, 1172 were interviewed. A key significance of this study is the clear provision of costs that PLWH incurred. These costs are direct costs related to transport, clinic fees, purchase of special food and other medication. Rosen et al (2007) have included indirect costs such as cost of substitute labour, loss of income and care taker time. However, indirect costs are beyond the scope of this study.

3.2.2.1 Treatment guidelines

Jones (2012) points out that health policy through guidelines may influence access. For example, clinical criteria require accessing a service such as diagnostic tests to determine one's CD4 count and or viral load before ARVs are dispensed. In Southern Africa, primary through to tertiary level health institutions can dispense ARVs on the provision that a CD4 count and or viral load tests are undertaken to determine the CD4 levels in the patient's blood. This has now been superseded by the new WHO ART Guidelines, which advocate that any person regardless of CD4 who tests positive to the HIV virus be put on antiretroviral treatment. Here diagnostic tests now become a mechanism to monitor a patients' drug response to viral suppression²¹ and have to be undertaken periodically. Thus, there is need for access to laboratory facilities to continuously measure their CD4, liver function and monitor other opportunistic infections and access to life saving antiretrovirals. This implies a cost to the patient where CD4 count and viral load machines or expertise may not be available and the patient has to travel to have these done before their ARVs can be renewed.

In discussing the quality of health as it relates to PLHIV, Vijayaraghavan et al (2007) note that using developed world standards for the treatment and care of HIV patients entails the commencement of treatment and monitoring of the patient's CD4 and the viral load is undertaken consistently every 3 months. Despite the above demonstrated potential benefits of the cost effectiveness of the use of world treatment guidelines very few African countries have the resources and capacity; human (including the technical knowhow) and financial to implement these ART guidelines on a universal scale given the fragile state in which their health sectors are in. The resources and human factor have a bearing on how we negotiate our everyday health related reality but more importantly also define our preferences in terms of type and form of health care commodities and services we seek to receive. It is therefore in this context that this study attempts to explore out of pocket payments that arise because of treatment seeking behaviour and the effects of such payments on poverty.

3.2.2.2 Cost of ARVs

Antiretroviral (ART) treatment is a key element in the management of HIV and AIDs in terms of both improving the quality of life through enhancing survival rates and by interrupting HIV transmission. (McEnery and Kresge, 2011); UNAIDS, 2010, Murkhjee, 2004, Madisodza et al, 2007, Burgoyne and Tan, 2008, Saunders and Volberding, 1997). Birungi et al (2009), Segundo et al (2007) and WHO (2006) have noted that ARVs also offer positive outcomes in terms of sexuality and reproduction for PLWH. Yet the high cost and demanding clinical requirements of these drugs is a barrier to their access by PLWH. In a mixed method study based on 109 respondents in Botswana, Weiser et al

²¹ Note on Guidance on the Phased Implementation of 2013 National Guidelines for Antiretroviral Therapy for the Prevention and Treatment of HIV in Zimbabwe (MOHCC, 2014), in Zimbabwe, National Drug and Therapeutic Advisory Committee (NDTPAC) and the AIDS & TB Unit, Ministry of Health and Child Welfare, Zimbabwe 2014:10.

(2003:5) found out that the majority cited the cost of ARVs and mentioned that they had skipped taking their medication due to the economic situation.

The economic related problems are, especially, acute in developing countries, where HIV infection levels are high and public resources are extremely scarce. Musgrove (2004) notes that the poorest countries tend to have the highest out-of-pocket spending as a percentage of income. The economic burden of illness due to out of pocket payments for treatment mostly affects the poor. In most poorly resourced countries, the failure of the state in Africa to consistently and adequately finance health care is due to a number of reasons. The most obvious is the modest tax revenues that limit spending on public health commodities and services, thereby creating a gap between ideal health investments and what can be afforded. The misuse of public funds cannot be discounted, as it lies in the heart of failure of the centralised post-colonial states as Wunsch and Olowo (1995) argued.

At macro, meso and micro-levels, it is important to note that in the Ukraine, for example, which has Europe's worst HIV cases, the number of those affected by lack of access to constant treatment above 15 years of age is said to be 360,000 (UNAIDS, 2009). One of the factors that have been attributed to this lack of access is government corruption and harassment of HIV drug users. In Zimbabwe, it would be the harassment of men who have sex with other men, whose access to life saving treatment is thus shaped by the existing political and social conditions. In such situations those affected have to travel elsewhere to seek services from institutions, organisations and individuals able to provide them without prejudice, in this case, the private health providers. In this context leaving no one behind in treatment coverage can be problematic if costs of treatment and care are borne extensively by the patient. It is obvious that health expenses, like any other payments, *ceteris paribus* will increase patients' costs, deter access and reduce their demand for care, as observed by Nahar and Costella (1998), Lewis (2000), Falkingham (2004), Sharma (2005), O'Donnell et al. (2005) and Xu et al (2003).

Jones (2012) argues that the issue of access can also be a rights based issue, which opens it to various interpretations which could include the policies that might enable or impede access. This can further be unpacked in social class terms where those in control of the instruments of service production determine the nature of access that other classes might have to their commodities by regulating the price of providing such commodities including ARVs.

In poorly resourced countries, it is common for HIV patients to pay over the counter in cash for ARVs and therapeutic medication to relieve symptoms or pain associated with taking them. They also pay for treatment of other infections, including opportunistic or chronic diseases. The observation by ZHAAUCT (2013:5) indicates that in some situations, health staff claimed to be short of required

ARVs as a way of soliciting a bribe or in order to sell the required commodity to the patient at a negotiated price;

Sometimes they tell you they do not have Effavirenz to go with Lamovidine and Zidovudine but can assist to get this from some source depending on how urgent you might be needing the medication, if you say you urgently require the effavirenz, they ask you how much you are willing to pay for it.

In a comparative study undertaken in Bangladesh, India, Nepal, Pakistan and Sri Lanka by Gray-Molina et al (2001), with the exception of Sri Lanka, it was found out that most payments made were to meet ex ante demands from providers. Bribes were requested in order to be admitted into the hospital or to obtain a hospital bed, as well as for receiving subsidised medications.

A study undertaken in Nepal by Wasti et al (2012), is of unique importance to this study as it illustrates that pill run out in by the health provider was one of the key reasons cited by participants for defaulting on treatment. The resultant reaction to ARVs and where a substitute cannot be provided by the health provider makes those in need of treatment to buy such commodities in the private sector normally at a high cost. In Malawi by Hosseinipour et al (2006:146) established that among other factors associated with dropping out from treatment was the high costs and toxicity of ARV treatment. In a study on the barriers to use of antiretroviral drugs in Rakai district in Uganda, Kunihiro et al (2010) found out from PLHIV that they lacked the awareness of free ARV's. This study is of relevance in that it is not only from another African setting, but it used a similar sample (n=384) and methodology (key informants and semi-structured interviews) similar to the quantitative sample size proposed for this study. It is of importance from the cause for direct costs to be incurred especially where patients have to seek health commodities from a subsequent provider at a higher cost. Basing on a retrospective cohort study of 304 patients initiated for antiretroviral treatment from a private clinic in Gaborone, Botswana, Bisson et al (2006) contend that the cost of antiretroviral treatment affected adherence the most.

3.2.2.3 User fees

The discussion of the financing mechanism is essential as it provides the degree to which households contributed directly to health funding and become key drivers of OPPs. Gaal et al (2011) writing on the Bulgarian health care system, Bredenkamp et al (2010), Bellia et al (2004), Ensor and Savelyeva (1998:43) on Russia and Tomini and Packard (2011) on Albania illustrate how informal payments become the basis upon which health care is obtained in circumstances where there is limited state support.

Prices affect consumer demand. When applied to health, the price elasticity theory and marginal theory of demand, indicate that user fees are needed only where the marginal value of an additional

dollar exceeds that from the private (commercial and traditional healer services). James et. al (2006) define user fees as “*official fees charged by public health providers for basic and higher level services*”. James et al (2006) advance the cause for user fees as a source of supplementary health financing modality, whose additional benefits include countering moral hazard by dampening consumption and improving consumption efficiencies in health care. In advancing this argument, it is asserted that user fees produce efficiency as resources get allocated based on the principle of supply and demand. That is if the price goes up the demand goes down. When this principle is applied to health care, it has a number of implications which infer that public health services are not efficient for the following reasons:

- i. The bulk of public health expenditure tends to be directed towards curative or treatment rather than preventive services. Treatment services tend to be expensive and as a result have a small coverage than preventive interventions.
- ii. If not regulated by price such as user fees, the demand for health services will result in moral hazard, that is, people will indulge in un healthy life styles under the notion that should they fall ill they will be treated. As a result demand for services tends to outstrip the supply of services or commodities.

This would lead to what Fredrick et al (2001) and Akin et al (1987) foreground as less unnecessary service utilisation by the patient. Mahal and Veerabhraiah (2005) see user fees not as a regulatory mechanism but a source of health financing that can be used to improve health services. This is based on their study in Andhara Pradesh VVP and Makarashira hospitals in India, which showed that the increase in investment through user fees could be beneficial;

The investment of APVVP funds has previously been extremely tardy, although it has been improving overtime – user fee reinvestment rates were barely 43% percent in 2001-2002. Raising to about 74 percent in 2003-2004.

What the above study highlights is that user fees can, if properly accounted for, be a resource for improving sustainability of health services. In the first instance, by reinvesting the monies collected to improve health services, both commodities and human factors can be bolstered. This presupposes that financial records of user fees collected and the expenses to which they are directed can be easily tracked and accounted for.

Yates (2006) advises on a more strategic use of user fees based on the following; the need to first provide a quality of health services that is demanded by the patient and secondly to avail health services in an affordable manner. Thus, the system can ensure that health services are affordable to

those below the poverty line. Lewis (2007) notes that out of pocket expenditures allow those who can pay to be able to access often higher-quality health care. This is based on their ability to seek treatment from private health care providers, where consultation fees and availability of other forms of treatment can only be afforded by a certain class of individuals. For this class medication can easily be obtained through private pharmacists after consultations with private medical personnel with adequate facilities, who undertake a comprehensive battery of tests.

The WHO (2010) has cautioned against user fees as payment for services provided and as a barrier to access to essential health services. In some cases user fees leads to financial catastrophe and impoverishment. Boyer et al (2009) observed that user fees affect negatively on the patient by interrupting their HIV treatment. Falkingham (2004:250) points out that user fees discourages use of services. Falkingham (2005) in a subsequent study demonstrates that consultation fees and admission fees can be a major out of pocket expenditure. In their criticism of user fees on policy, McIntyre et al (2006) cite the turnabout by the United States and the World Bank; and the lobbying against user fees by the British Department of International development. The demand of user fees results in impoverishment as individuals or households struggle to meet the cost by selling assets and cutting back on other social expenditures. Gilson and McIntyre (2005) advocate for the removal of user fees. They see user fees as a regressive form of health financing. They suggest that national governments increase funding to fill the void left by user fees. In this way, such funding would counter the demand for services that would have been supported by user fees and ensure that the services are not compromised. They recommend that the withdrawal of user fees be made public to prevent health staff that might continue to charge user fees perhaps for rent seeking purposes. The value of this argument lies in that, the authors do not present an abstract proposal but base their recommendations on examples on the success and failure of user fee withdrawal in the region.

A study by Koaunda et al (2010) in Burkina Faso on “*User fees and access to ART treatment ...*” revealed that access to services was affected especially when they were paid for. Beyond this statement, the study does not elaborate how. It would have been useful if Koaunda et al (2010) have provided more information as their study involved PLWH on ART. This could have further enriched the current study in terms of noting the treatment seeking behaviour and consequences that befell the study population in the Koaunda et al (2010) study. The Zimbabwe Association of Doctors for Human Rights (2009), and Whiteside and Lee (2005) have noted that user fees are an impediment towards the provision of treatment. This view is shared by Murkhjee et al (2006), Whalton et al (2004), Weiser et al (2003) and Mwanza (1999). Johnston (1998) found out that, in Zimbabwe, user fees had not improved the quality of services and had in fact caused inequity to arise in the use of services. The impact on the income of households particularly of the poor can inhibit access to services. Largarde and Palmer (2008) argue that people often weigh the value of out of pocket spending in relation to the

value gained by improved health services. This is notable, especially where it can contribute towards further impoverishment as individuals or households struggle to meet the cost of user fees by selling assets and cutting back on other essential social expenditures.

3.2.2.4 Absence of health insurance

Banerjee and Duflo (2007) note that formal health insurance in developing countries are under developed and that formal and credit savings are limited. That is, social protection mechanisms such as health insurance to cushion the cost of illness on the individual or household are scarce in Africa. In the absence of health insurance to smooth consumption, households incur income shocks due to health costs. In the context of this study, it is important to note that while there may be many private health insurance schemes in Zimbabwe; these serve only 10 percent of the population, who are mostly in the formal employment sector.

Health insurance or social protection measures in place also help to ensure that cost burden of illness can be mitigated thereby preventing households to be exposed to income shocks. This can result in them resorting to coping strategies such as selling assets or borrowing to meet the treatment costs. Health insurance thus provides a kind of saving that can be requested to offset treatment costs such as user fees, transport or procurement of health commodities.

3.2.2.5 Access to treatment

In the conceptual framework to analyse the economic burden of illness, Russell (2004:148) does not define access in box 6, except to locate it in the boarder health determinant factors. The word access is a complex multi-layered word in meaning which allows it a broad and simple generalization. Jones (2012:29) defines access as the “ability to get”, “have or use something”. The issue of access can also be a rights based issue as Jones (2012) elaborates, which opens it to various interpretations which could include the policies that might enable or impede access to treatment. These can be located in the political economic and health spheres where access to the social production of health determines the provision of commodities such as ART. Lewis (2007) notes that the ability to pay out of pocket allow patients who can pay to be able to access often higher-quality health care. This is based on their ability to seek treatment from private health care providers, where consultation fees and availability of other forms of treatment can only be afforded by a certain class of individuals. For this, class medication can easily be obtained through private pharmacists after consultations with private medical personnel with adequate facilities, who undertake a comprehensive battery of tests.

In whatever context one wishes to locate access, it has a definite cost which can be direct, for example when one focalises the means towards attaining it. For purposes of simplicity our inference to access is restricted to the modus operandi of seeking a health service or commodity which in simple terms involves transport or distance and the direct costs associated with this.

3.2.2.5.1 Transport

The time taken to get to treatment centres and the distances involved exert a strong influence on decisions to take up and continue with treatment. Jones (2010) contends that spatial or geographical locations have an implication on access. The spatial or geographical location of a health service provider will affect how services are accessed. In some instances this will require that transport be sought to go to the health service provider. Physical location of health service or commodity as to point of access was acknowledged by WHO/UNAIDS (2007, 2008, 2009) as being a determinant factor towards access to treatment. According to Ware et al (2006) transportation costs are multifaceted as they include gasoline or transportation costs as well as the opportunity costs of spending hours or even a whole day in travel.

The challenges of transport in accessing ART, was noted by Berutti et al (2012) in a study on out of pocket payments for treatment in Tanzania. Tuller et al (2010) cited transportation as one of the major out of pocket expenses that were a barrier towards the uptake and adherence of antiretroviral treatment. Tuller et al (2010) used open ended interviews with 41 participants, to determine structural health service barriers to adherence and access and these were attributable to transport related costs. The sample chosen by Tuller et al (2010) involved 25 women and 16 men, whose ages ranged between 24 to 57 years. Of those interviewed, 23 participants were from the rural areas, 12 from peri-urban and 6 from urban areas. The singular aim of the study was to understand the role of transportation as a structural barrier to adherence and treatment to ART. The sample was suitable as it was not too broad or too small to make regional inferences. The authors provide a clear presentation of evidence from the in-depth interviews, which gives the study a clear focus and coherent structuring of argument that leads to a conclusion that meets its aims and objectives. The study is useful because it quotes extensively from the in-depth interviews of the participants to substantiate its findings on themes related to non-adherence and coping. Travel costs and distance affected the regularity with which participants in the study were able to attend clinical reviews as well as access medication on a monthly basis. This caused other psychological problems such as stress and anxiety. Questions about how to raise transport fares need to be juxtaposed with other competing physiological needs, such as food, housing and school fees, which also affect households. Transportation costs were cited by Mukherjee et al (2006), Ware et al (2006), Nhelma (2003), Worrall et al (2003) as a barrier to treatment access which compromise both access to care and ARV adherence, and ultimately the health of the patients. Joglekar et al (2011), in a qualitative study in India, found that finding money to pay for transport was a problem for patients to undertake routine monthly visits to collect their supply of ARVs. What this study illustrates is that the direct cost associated with transport can affect individuals to be able to access ARV treatment. Although set in India, the study is useful as the sample size and methodology used closely resemble those used in the qualitative part of this study. Perhaps a drawback of this study was in not providing some quantification of the direct costs of transportation.

Miller et al (2010) note from their qualitative cohort study of 528 patients that defaulted treatment was caused by transportation costs.

Rosen et al (2006) also note the significance of transport cost in their study done in South Africa. In one setting in Malawi, where all public health facilities are located within 6 km of the population and where care is provided free-of-charge at the point of delivery, it was established by Mann et al (2002) in McCoy (2003) that on average, patients spent up to US\$13 accessing a Tuberculosis (TB) diagnosis test. In Zambia, Russell (2003) and Needham et al (1998) established that average indirect costs related to pre-diagnosis of TB were close to US\$27. Patient treatment was interrupted when the cost of treatment became unaffordable, as noted in studies undertaken by Johansson et al (1999), Khan et al (2000), Greene (2004) and Watkins et al (2004).

In some cases, it took more than a day to access free medication from a clinic or hospital. Nhlema (2003) and Worrall et al (2003) contend that distance to health facilities also affects access to treatment and care. In a study of 109 patients and 60 healthcare providers in Botswana, that used both qualitative and quantitative methodologies to find out the barriers to antiretroviral adherence, Weiser et al (2003) found out that 10% of the sample cited travel and migration costs and 44% cited financial costs.

In a study on the barriers to the use of antiretroviral drugs in Rakai district in Uganda, Kunihiro et al (2010:124) noted the long distance to treatment centres as a barrier to access treatment. A study undertaken in Nepal by Wasti et al (2012) also had a similar conclusion. Of unique importance to this study is the identification of not only transport costs and side effects but patients run out of pills and they get busy as reasons for non-adherence to treatment.

Although HIV patients may have subsidised ARVs, Koanda et al (2010) demonstrates that the issue of access to treatment goes beyond just transport and free access. The study noted that 16% of HIV patients without income and 21% of those unemployed paid for ARVs. The cost of drugs for opportunistic infections, food and transport were cited as economic burdens by 85%, 91% and 71% of the respondents who did not pay for the ARVs. McIntyre et al (2006) point out that indirect cost associated with treatment such as travel, food and accommodation can, in fact, be higher than the cost of treatment itself. However, there is a tendency to under report this. The importance of the study by Kounda et al (2010) lies in that, it goes beyond user fees as a barrier to access. The study shows the cost according to type of treatment and related activities. This makes it possible to make an analysis on whether the economic costs provided were catastrophic especially for people with no income and the unemployed. That is, if one is to assume the transport cost of USD1.4 among other costs identified in the study were monthly. The above studies are relevant to the situation in Zimbabwe where, although ARVs are meant to be free, direct costs incurred through transport can be an economic burden given the fact that most of the population is either unemployed (WFP, 2012) or working in the

informal sector (Shamu, 2012) where wages are unpredictable. The limited fiscal space and emergence of a large informal sector estimated to be 60%²² or above 70%²³ means that the Zimbabwean state has not been able to raise enough money to support adequately the supply side of the health sector.

3.2.3 Coping strategies

Russell (2004:151) defines coping strategies as “*actions that aim to manage the costs or process (e.g., illness) that threatens the welfare of one or more members of the household*”. These coping strategies can result in direct or indirect costs to the household. Flores et al (2008) notes that borrowing and selling of assets provide a coping mechanism whereby households respond to health shocks, and how payment may affect their future welfare. Alam and Mahal (2014) have argued that the economic burden of illness necessitated households to resort to various coping mechanisms such as income, saving, borrowing, using loans or mortgages and selling assets and livestock to be able to meet out of pocket health spending. More empirically, Gotsadze et al (2005) show that the financial burden created by out of pocket costs can affect access to health services and commodities based on their study of the Georgian health system. They argue that the coping strategies resorted to mitigate against the economic burden of illness often resulted in households experiencing a diminished state of economic and health being. According to Gotsadze et al (2005), households that lacked the means to meet health care related costs resorted to various coping strategies, chief among them being, borrowing from friends or relatives as 70% of the respondents in their study indicate; 10% sold a valuable household asset and or another 10% another household good (Gotsadze et al, 2005:5). Malik and Syed (2012) have also shown that households faced with ill health may borrow, sell assets and or divert resources from other needs in order to meet the cost of health care. As similarly noted by Joglekar et al (2012), where 50% of their respondents cited financial constraints for not being able to go for their ARV stock replenishment. The study purposeful population cited use of money for other household expenses. In spite of being helpful in the understanding of some of the costs that affected access to treatment, the study would have been more enriching if it had included narratives to support its results.

Borrowing and selling of assets as a coping mechanism for funding health has been documented by Russell (2004), McIntyre et al (2006) and Peters et al (2001) as contributing towards structural poverty, especially for the vulnerable, as highlighted by Kipp et al (2006); Ngalula, et al (2002); Piot et al (2007). From some of the literature, there is a link between borrowing and impoverishment as noted by Jacobs et al (2012), McIntyre et al (2006), Kruk (2009), Russell and Gilson (2006) and Russell (2004). For example, the over-reliance on out-of-pocket settlements

²² According to the Centre for International Private Enterprise and the US Chamber of Commerce cited in the Standard of 3-10 October, 2010.

²³ Shamu (2012:4)

for health related chronic illnesses such as HIV can result in deterioration of a household's standard of living, as argued by O'Donnell et al (2005) (2007), Xu et al. (2003), Gerfter and Gruber (2002). Gotsadze et al (2005:5) highlighted the lack of financial means as being responsible for 60.1% of the respondents in their study to self-treat themselves as a cheaper alternative to visiting a health care provider. The study notes that the prescription drugs could be obtained directly from the pharmacies without the need to have a doctor's written consent. Goudge et al (2009) point out that in some instances households will opt for traditional or sub optimal care in order to forego the cost of accessing conventional health care.

The coping strategies above are broad categories adopted by households to withstand the economic shocks caused by ill-health. In the study the dimensions of coping below are analysed based on the work of Russell (2004), McIntyre et al (2006), Flores et al (2008), Malik and Syed (2012), Alama and Mahal (2014). The thrust is that households will resort to borrowing and selling of assets to mitigate the effects of cost of treatment.

3.2.3.1 Borrowing

The literature on borrowing as an out of pocket financing mechanism for health is sparse (Jacobs et al. 2012), more so if it is related to HIV in an African setting. In Cambodia, the Demographic Health Survey (2010) revealed that 18% to 36% of the Cambodian population borrowed to pay health costs. These findings are supported in a qualitative study by Ir et al (2012) that showed that a large proportion of Cambodians borrowed to pay for health costs including the payment for HIV treatment. The study goes in into detail to show the type of debts incurred and the effects these debts had on households. This qualitative study provides extensive quotes that describe the nature of indebtedness and poverty among the affected households. There is a simplified flow chart on the economic consequences of illness in which the direct costs are medical expenses and transport. Indirect costs relate to income loss. Russell and Gilson (2006) observed that health costs of 2.5% to 5% of monthly income precipitated the need to borrow. De Waal and Whiteside (2003) have been critical of borrowing and other coping strategies such as lowering the food consumption of adults. Borrowing, for example, may result in negative externalities when the household becomes entangled into an inextricable debt trap. Most studies on coping strategies on out of pocket financing mechanism have shown that borrowing is one of the mechanisms used by PLWH to finance direct and indirect costs of treatment. However, most have not been able to demonstrate the short, medium and long term implications on household domestic capital formation and accumulation. Borrowing money implies that it will have to be repaid at some time, and thus it becomes a source of economic discomfort and social disruption, which can be manifested in stress.

3.2.3.2. Selling of assets

According to Jayne et al (2003, 2004) when households sell household goods including tools they become vulnerable to poverty. Ill health caused by HIV increases demand for health related services and commodities, while simultaneously affecting the household's discretionary income. Due to the expenditure shocks associated with ill health caused by HIV, households have had to adjust their level in terms of fiscal space. Thus changes to the financial dynamics to meet these costs often result in reduced consumption of other needs. In some cases, assets have been sold to meet the cost of treatment or defray expenses associated with other treatment related costs. Gotsadze et al (2005) noted that where households were not able to borrow to pay for health care, they sold an asset which might even be of sentimental value. Kazinga and Udry (2006) observed that in Burkina Faso, some of the assets sold to cope with health shocks include livestock. In this study, it can be shown that the unemployed and those residing in high density areas receive the least health care, and seem to bear the brunt of the costs associated with treatment. According to Hart's (1971) inverse law, the poor are the people mostly in need of health care.

Although this study is consistent with the studies from other countries, the Zimbabwean case brings to the fore a lot of nuances that makes this study different in that borrowing as a coping strategy may not necessarily be effective on its own to offset the direct costs/OPPs associated with treatment seeking behaviour. In addition, the study quantifies the amounts that are borrowed and the type of assets that are sold to pay for treatment seeking behaviour and how these also impact on the household livelihood. Furthermore, the research analyses whether there are strategies beyond borrowing and selling of assets that are used to cope with health shocks.

3.2.4 Impact and consequences of direct costs

According to the literature, out of pocket payments have been attributed to the deterioration of household standards of living (O'Donnell et al, 2005; Xu et al 2005; Gerter and Gruber, 2002). In a cross sectional study of fourteen Asian countries including Bangladesh, China, India and Vietnam, O'Donnell et al. (2005) documented that out of pocket expenses affected a large proportion of household resources in these countries through health care payments, and this caused impoverishment. This is further illustrated and supported in studies by Xu et al (2003), Gertler and Grubler (2002). It has been argued by Alam and Mahal (2014) that the impact of out of pocket payments for treatment or health care in general may not be confined at a micro level but might impact macro level development and growth. In a study done in the Matopo region in Zimbabwe, Skovdal et al (2013) reveal that HIV affected families often experienced food insecurity. Bandara et al (2015), Beegle et al (2006), Basu and Van (1998) among others have documented how poverty caused by ill health can lead to child labour as either (luxury axiom) or (substitution axiom).

The catastrophic effects at individual and household levels have been defined by Pradhan and Prescott (2002); Xu et al (2007), Wagstaff and van Doorslaer (2003); Russell (2004); van Doorslaer et al.(2007) as a portion or percentage of household expenditure spent on health care within the range of 0% to 10% of household expenditure directed towards health expenditure. Alam and Mahal (2014) have argued that out of pocket payments can be deemed catastrophic if they exceed a certain threshold of household 'capacity to pay'. Sakesena et al (2010) have argued that a range of 0% to 30% might be catastrophic. Doorslaer et al (2006) and Mendola et al (2007:5) have argued for a range of 0.05% for Asian countries and 2.8% for 5 Eastern European countries or using the World Bank poverty line of USD1/day for Asia and USD2/day for the five European countries. Xu (2005) suggests a comparison of expenditure directed towards HIV care and that of the household expenditure for non-essential items. It is important to observe as noted by Russell (2004) that the percentage or proportion spent on health in relation to individual or household income is relative to the resources available to the individual or household. 10% expenditure on health may not be catastrophic in a 'rich' household that would simply cut back on luxuries. Hortsberg (2003) and Trujillo (2003) propose the use of household expenditure as a proxy for income to determine if health expenditure is catastrophic. This level of analysis will be relevant to this study, especially Zimbabwe to determine whether out of pocket caused by various treatment seeking behaviours can be catastrophic. In this vein, the analysis offered by Doorslaer et al (2006) and Mendola et al (2007:5) will be useful in the context of a country like Zimbabwe with a large informal sector lacking health insurance and where there is a high unemployment rate in the formal sector. The poor lack savings to fall back on. The situation can be exacerbated by high health expenditures in relation to that available for the household as Banerjee and Duflo (2007) assert. Hortsberg (2003) and Trujillo (2004) suggest using health spending as a proportion to household expenditure to determine whether costs are catastrophic. In this case household expenditure is used as a proxy for income. These costs can overwhelm households resulting in consumption not being able to be mitigated in a Pareto optimal manner

3.2.4.1 Poverty as a consequence of out of pocket and or coping strategies

The consequences for households of both (a) the direct cost of treatment and (b) coping strategies can lead to poverty as McIntyre et al (2006) allude to. Russell (2004) points out that this will have an impact on household's livelihood such as assets and food security which might be affected. In their conceptual framework Alam and Mahal (2014:3) show that out of pocket payments for health are related to catastrophic expenditure. This necessitates the need for coping strategies which had a detrimental effect on consumption which contributed towards poverty. Socio-cultural factors which influence treatment seeking behaviour can also be contributory factors to Poverty. This often occurs through direct costs for seeking health service or a result of coping strategies that this entails. Poverty results from multiple causes; from a health perspective, the loss of income due to ill-health according to Pitayanon et al (1997), Bachmann and Booyesen (2003). Ngalula et al (2002) and Mutyambizi

(2002) argue that in some instances households are impelled to sell productive assets. The high cost of health spending particularly at household level can have serious effects as Hotchkiss et al (2005) noted.

The definition for poverty has been nestled in monetary metric measures which are computed or imputed and informed by a neo classical theory of consumer choice which emphasises utility and consumption at individual level. Mafeje (1999) argues that when such a measure is applied to Africa, there are a lot of inaccuracies. This is because, production and value are all shared among socially defined groups, where metric measures may fall short in providing an index of complex social realities. Sachs (2005:20) makes a distinction of the levels of poverty which are extreme, moderate and relative poverty. Extreme poverty is where the household lacks the means to basic services such as health access, experiences constant hunger, and does not have access to safe drinking water and sanitation, shelter, clothes and shoes. Such a household is unable to send children to school as Sachs (2005:20) argues. Moderate poverty is the ability to meet these minimal physiological needs. If these minimal standards were to be quantified they would be equal to the World Bank measure of US1 to US2 per day required by an individual to subsist. This definition by Sachs (2005) does not reduce poverty to physiological needs. It does acknowledge other forms of basic needs that are essential to human resource investment and social reproduction such as access to information and human rights. Poverty has a range of meaning and dimensions, which make it difficult to conceptualise without reducing it to basic needs required for survival (Naidoo, 2005). Chambers (1998) has sought to link both tangible and non-tangible aspects of socio-economic hardship in defining poverty. Perhaps in recognition of this difficulty and the need to avoid a reductionist view of poverty into monetary metric measures, The United Nations Development Programme (UNDP) has developed an Index that include among other social aspects, access to information, education, communication and culture. These are key components to human development and poverty alleviation. The need to provide an in-depth discussion of poverty from a health perspective is based on the fact that out of pocket payments can be catastrophic and can lead to poverty. Direct costs emanating from treatment seeking behaviour singularly or in conjunction with such coping strategies as borrowing and selling assets can result in asset depletion and lack of capital accumulation and savings. The discourse on poverty gains relevancy as it has serious ramification in the way the data from this study can be located to illustrate the degree of poverty particularly in the context of Zimbabwe. Here metric measures alone cannot be able to depict and provide an accurate index of such a complex reality. For example, according to the 2011/12 Poverty and Poverty Datum line Analysis 73%²⁴ of Zimbabweans were poor. UNDP Human Development Reported (2012:19), 94% of paid employees in 2011 were receiving remuneration below the total consumption poverty line (TCPL)²⁵ of USD428 per month. According to Poverty

²⁴ Poverty and Poverty Datum Analysis in Zimbabwe 2011/12, April 2012, ZIMSTATS.

²⁵ USD427.82 (Labour Force Survey, 2011).

Income Expenditure Survey (PICES, 2011/12:79), 77% of employed Zimbabwean households earned a gross monthly salary of USD350, with only 4.5% earning above USD800.

Access to employment is closely associated with poverty. As a result of high formal unemployment, the country has witnessed a large informal sector developing. According to PICES (2011/12:97-98), in Zimbabwe, 3.7 million people are involved in the informal sector. PICES (2011/12:74) noted that a household headed by someone in the informal sector was likely to be poor in both urban and rural areas. International Labour Organisation (ILO, 1991) explains the cause of the informal sector as:

The inability of other sectors of the economy – agriculture or other rural activities on the one hand and modern industry and services on the other – to provide adequate incomes or employment to a rapidly growing labour force.

The ILO (1991) cited in Mhone (1996:1) points out that the informal sector:

Tend to have little or no access to organised markets, to formal credit institutions, to formal education and training institutions or to many public amenities; they are not recognised, supported or regulated by the government; they are compelled to operate outside the framework of the law, and even where they are registered and respect certain aspects of the law they are almost invariably beyond the pale of social protection, labour regulation and protective measures at the workplace. Informal sector producers and workers ...generally live and work in appalling, often dangerous and unhealthy conditions, even without basic sanitary facilities.



An informal trading sector site: Picture by Nyasha Nyahoda

Mhone (1996) argues that because of the above conditions that prevail and give rise to the informal sector, it is a residual sector and an employer of last resort, which has inherent inadequacies and deficiencies. It is important to note that unlike the Rostowian assumption that views the informal sector as part of the dualistic economy prevalent in under developed countries, this sector is part of the main economic set-up although it tends to be marginalised. It is marginalised in the way it has access to formally structured economic and social Amin (2007) points out. The importance of this sector lies in the following; its very nature and size will influence the study results in terms of describing and explaining the attendant direct costs/OPPs of treatment seeking behaviour and how they impact on PLWH.

As a result the treatment seeking behaviours and costs of treatment incurred out of pocket have to be placed in the context of this sector. It has to be borne in mind that, according to PICES (2011/12:79), 50.5% of the poor used public health facilities. Private health providers such as doctors, laboratory personnel, radiologists and pharmacists among others are bound to require cash payments as this sector has no health insurance.

3.3 Conclusion

The above texts, among them Russell (2004), McIntyre et al (2006), Rosen et al (2007) have produced different forms of epistemology which help to provide an indication as to the direction that the study will take. The above mentioned scholars define the treatment seeking behaviour, which include the issue of adherence and costs that result from out of pocket payments; the coping strategies they entail and the attendant impact they have on livelihood. The overall health system in place has a major influence on treatment seeking behaviour. The literature review has provided the conceptual framework which will guide this study. More specifically it has outlined the key socio-cultural categories (stigma, traditional beliefs, and institutional factors namely waiting time and stock outs) which will be used to measure treatment seeking behaviour and also how this influences direct costs. The categories related to costs which this study will measure with a view to show their catastrophic nature are transport, diagnostic tests, cost of ARVs and absence of health insurance. The study also focuses on how they impact on households in terms of coping strategies and poverty in general. The extensive discussion of poverty has been necessitated by the fact that poverty and HIV are in a cyclical relationship, where HIV can fuel poverty, which in turn can be a causation of HIV as households seek means of survival.

Chapter 4: Research design and methodology

4.1 Introduction

According to Morse (1991:122) “...research methodologies are merely tools, instruments to be used to facilitate understanding”.

This chapter begins by describing and justifying the research design for this mixed method study. The chapter highlights how the sample was chosen for both the quantitative and qualitative data collection processes. The chapter then deals with the operational issues such as how data was collected using quantitative and qualitative methods as well as the analysis of the data. The chapter will also provide how the recruitment of the study population was done; bias and ethical issues will be discussed.

4.2 Research design

This mixed study was done in two phases with the first being informed through a positivist approach which was based on the use of a questionnaire and followed by a qualitative approach based on the use of a semi structured interview schedule administered through key informant interviews. This mixed method study is characterized by an initial quantitative analysis followed by a more in-depth qualitative analysis to detail, interpret and explain the quantitative results. Together the quantitative and qualitative results help us to better understand the experiences of those living with the situation under investigation ~~a or a process~~ according to Creswell et al. (2003:228).

Furthermore, the justification for using such an approach is based on the need to provide holistic perspectives to avoid reducing human medical experience to single dimension descriptors as has been argued by Navarro (1976). Ainsworth and Semali (1998) observe that considerations of socio-economic conditions have a threefold effect; that is, improving the targeting and effectiveness of preventive efforts, assessing economic impact (on production and on the cost of treatment) and devising better coping strategies. Russell (2005) justifies the use of other methods that can complement quantitative methods especially where the study involves economic burden of illness and poverty. Kelly in Regan (2006:260) argues that the poor are the most vulnerable to HIV infections as a result of poverty, where there is less scope in their lives for making real choices affecting areas related to their social and economic situation. That is, the choices that they make concerning where and how they live, how they spend their earnings, how they will occupy themselves during free time are shaped by the material conditions that prevail in the environment in which they are.

The research question demands that generalizable data aimed at describing patterns and gathering rich data is aimed at understanding the complex decisions individuals make based on their interpretation of the situation. In the context of this study, this approach was deemed necessary because of the

economic burden costs associated with treatment seeking behaviour which results in OPPs. The costs require that PLWH adopt certain coping strategies that have a profound bearing or impact on their livelihoods. Statistics on the cost by provider type and proportion of average income spent on treatment seeking behaviour, is useful but provides only part of the story. The descriptions of how coping strategies and out of pocket payments have impacted on households as outlined by the research question and scopes of the study below are pertinent.

4.3 Sampling frame and sample size

4.3.1 Quantitative sampling method

From the 88,462 adult patients on ART in the Harare Metropolitan Province (NAC, 2011) across 12 districts and 94 wards under 4 local authorities, namely Epworth Local Board, Ruwa Local Board, Chitungwiza Local Authority and Harare City Council (NAC 2011:7), a sample size of 383 was calculated using a confidence level of 95%, confidence interval of 5²⁶ with a target population of 88,462, giving a sample size of 383 which was used and ensured representation from all the districts or constituencies in Harare Metropolitan Province.

4.3.2 Qualitative sampling method

From the completed questionnaires, depending on the completeness of information provided, the respondents were asked if they would be willing to participate in long interviews, in which they would be asked for more detailed information on what factors influenced their treatment seeking behaviour (tsb) and how payment for out of pocket payments affected their household budgets. The sample was taken from the fifty four who indicated willingness to be interviewed in detail, then narrowed down to 20, who were selected using maximum variation sampling²⁷ resulting in 16 respondents being interviewed 9 male and 7 female respondents. The rationale was to interview a very different selection of PLWH who were paying for treatment based on type of health provider, gender, geographic location, marital and employment status. Lincoln and Guba (1985) advocate the use of maximum variation sampling as the most useful strategy for qualitative research. This sampling procedure aims at capturing and describing the central themes or principal outcomes that cut across a great deal of participant or program variation. In concurrence with the above views, Sin (2010:313) suggests that the spread of participant characteristics enhance the applicability findings in other contexts. Marton and Booth (1997) advocate the maximization of the conceptual variations of participants to ensure adequate data for deriving an optimal set of categories.

²⁶ This sample size was calculated using GPower 3.0.10: Sample size calculator, 2009. <http://www.surveysystem.com/sscalc.htm>], Accessed 5 June 2011

²⁷ <http://www.sfu.ca/~palys/Purposive%20sampling.pdf>

4.4 Data Collection Methods

After the Medical Research Council of Zimbabwe granted research approval on February 22nd 2013, (see Annexel) support group leaders and focal persons in organisations working with PLWH completed the questionnaires in the various districts of Harare Metropolitan province (Harare City, Chitungwiza, Ruwa and Epworth) between April and June 2013. Data collection ensued beginning with the collection of quantitative followed by the qualitative data collection.

4.4.1 Quantitative data collection

Quantitative data through use of the consent letter and questionnaire (see Annexe 2) it was important in so far as it helped to measure the economic burden of illness caused by treatment seeking behaviours by finding out the;

1. direct costs/OPPs of illness that PLWH in the HMP incurred by provider type and whether these could be deemed catastrophic.
2. number of PLWH who resorted to coping strategies such as borrowing and selling an asset to be able to deal with the cost burdens.

4.4.1.1 Rationale for use of questionnaires

The above data was collected using questionnaires. In the context of this study, the rationale for using questionnaires was based on the following considerations;

1. Data collected this way measured the reactions of many people using a limited set of questions, according to Patton (1987), which made it possible for comparisons and statistical aggregation of data to be done on identifying the out-of-pocket expenses, their distribution and median cost such as: payment for service, ARVs, laboratory tests, traditional healers and mode of payment used (cash or health insurance).
2. They were easy and cheap to administer, large and small organisations of PLWH such as the Zimbabwe HIV/AIDS Activist Union Community Trust (ZHAAUCT), Zimbabwe Network of People living Positively with HIV (ZNPP+), Women AIDS Support Network (WASN), National AIDS Council, Love Foundation and Life Empowerment Support Organisation (LESO) used their staff across the 12 districts and 94 wards under 4 local Authorities namely Epworth Local Board, Ruwa Local Board, Chitungwiza Local Authority and Harare City Council.
3. It enabled the researcher to give the study participants time to complete the questionnaires and time to consult other sources of primary and secondary information before responding to questions.

The questionnaires were completed at the participant's convenience and this helped to improve the response rate. The high response rate can be attributed to the fact that there was constant follow up on the questionnaires to ensure that the desired sample was met. This meant that the research assistants had, in some cases, to go back several times to be able to collect the questionnaires from the known respondents.

4.4.2 Qualitative data collection

The study also collected qualitative data to compliment the quantitative data. Strauss and Corbin (1990) claim that qualitative methods are better used to understand any phenomenon about which little is yet known. In this case the treatment seeking behaviours and patterns among PLWH on ART in Harare Metropolitan Province and the factors influencing them are not known. In addition the participants' experiences paying out of pocket payments for treatment and health care in general, "*may be epistemologically in harmony with the reader's experience*" (Stake (1978:5). Furthermore, Robson (1997) and Bogdan and Biklen (1997) argue that qualitative research deals with immeasurable data. Robson (1997:227) states that;

When carrying out an enquiry involving humans, why not take advantage of the fact that they can tell things about themselves.

This view is further supported by Jones (2004:97) who asserts that one of the virtues of qualitative research is its inclusionary nature and the ability to give service users a voice through the research process itself. Scheff (1997:33-36) emphasises that the use of qualitative research is not an exercise in truth or falsehoods, however, these investigations are poly-vocal attempts at interfacing with cultural/relational/linguistic accounts of the real. Hiatt (1986:737) argues that the essence of this methodology is based on the fact that:

There are efforts by the mind to concretise meaning and the qualitative dimension has an integrative function for the researcher. Unity provides context and meaning and it is toward such unity that the researcher is striving. Qualitative efforts make use of that part of the person concerned with meaning, truth or purpose reality-the ultimate significance of things.



Qualitative research sometimes involves recording interviews: Picture by Bezel Jabulani Muchovo

Although qualitative research has often been criticised for not being generalisable beyond individual cases, there is an emerging consensus typified in the works of Sandelowski (1986) and Erlandson et.al (1993), which suggests that the constructs generated from this type of methodology are transferable in terms of the extent to which findings can be applied to other contexts. . Strauss and Corbin (1990) claim that qualitative methods are better used to understand any phenomenon about which little is yet known. This study describes and explains data that is difficult to convey or extract quantitatively, which can provide new perspectives on how certain phenomena might be known to function. This is the case with the information and explanation on:

1. How cost burdens through direct costs/OPPs exert pressures on house hold budget?
2. How PLWH manage to cope with these cost burdens and the consequences on household livelihoods as a result of :
 - a) The direct costs of treatment seeking behaviour and
 - b) In terms of their resilience (food security, diminished savings and poverty).

4.4.2.1 Rationale for key informant Interviews

Interviews were held with sixteen respondents which lasted approximately 50 minutes to one hour; a voice recorder was used with the participant's consent. Field notes were also used by the researcher on the key informant guide (See Annex 3, 4, 5 and 6).

- I. The rationale for using key informant interviews was premised on the fact that they afforded privacy and an opportunity for respondents to freely express their sexual behaviour, which in a focus group, some might find embarrassing to articulate yet such information would be of importance in providing substance to the quantitative data.
- II. While others might feel embarrassed to reveal their coping strategies such as borrowing and the type of asset they sold.
- III. In some instances, they would not want to reveal the impact of economic burden of illness such as the number of meals they eat or whether they were defaulting for fear of being ostracised.
- IV. The researcher was mindful of the contracting political space in Zimbabwe, which has in place various instruments of cohesion and oppression. The most notorious is the POSA²⁸. In keeping with the need to keep the informants from harm, as indicated in the consent form and as part of the ethics, focus group discussions were ruled out as an option for data collection.

A semi structured interview guide was used to collect data until saturation. The purpose of using the qualitative study through detailed interviews was to gather data on the experiences and effects of direct costs/OPPs including the effects on household budgets and catastrophic costs due to PLWH motivations and reasons for their treatment seeking behavioural decisions. That is, PLWH make the difficult choice of spending more to access better care or care at all. A semi structured interview guide was developed to guide the researcher, to ensure the key aspects required from the interview were covered. The interviews were conducted at the participant's residence; the central questions were; *"From a previous study done it was found out that PLWH are paying out of pocket for treatment related services; why and how did you decide to pay on your own out of pocket?"* Interviewees were experts in their owned lived experience of paying out of pocket for HIV related treatment costs. As such they needed to be asked a question at a time which would be probed further if need be for information such as:

1. What were your reasons for opting to buy the ARVs on your own? And why?
2. Is there stigma in your church? How do you know? What is the church position on this matter?
3. Describe these queues? How inconvenient where they? Did they compel you to skip them?
4. What makes you afraid of defaulting on treatment?
5. What other reason made you decide to consult a traditional healer? What made you opt to use traditional medicines instead of continuing on ART?

²⁸ Public Order and Safety Act of 2001 which gives the police and intelligence services the right to arbitrary arrest and detain without trial any gathering of more than three people perceived to be a security threat or making utterances that can undermine the state such as complaining about services.

6. What has motivated you to be able to buy your own ART? How has it affected your household budget?

4.5 Data analysis Methods

4.5.1 Quantitative data analysis

The data from the questionnaires was entered using software called EPI-Inf 200 V.3.5.1²⁹ for analysis and presentation. The choice of the software for undertaking this analysis was based on the following consideration:

1. The researcher was familiar with the software and could easily work back and forth to generate the desired analysis and presentation using the software without external support.
2. Could modify and define the search categories appropriate in answering the research question and its objectives.
3. Could easily go back and re-enter data that was incomplete where necessary.
4. The data involved did not require complex analysis, which would have meant use of other more sophisticated software and support.

4.5.2 Qualitative data analysis

Data from key informant interviews was transcribed from tape and analysed using the Thematic Analysis Approach.

4.5.2.1 Justification for manually transcribing the interviews

These interviews were audio recorded and transcribed verbatim. Several advantages accrued from transcribing the tapes verbatim viz:

1. Fear of losing the finer details and nuances of the interview in the process of using software to interpret and organise the data which was not in accordance with the desired flow.
2. Poor quality of output from transcription software, especially where local languages were used as demonstrated in the pilot study. Furthermore help in coding the data was provided by the research assistant who had helped with the quantitative data analysis.

4.5.2.2 Rationale for using a thematic analysis approach

Braun and Clarke (2006:6) define the thematic analysis approach (TAA) *as a method for identifying, analyzing and reporting (themes) within data*. Braun and Wilkinson (2003:20) further assert that *thematic analysis is applied to qualitative data where analysis seeks out commonly recurring themes*.

²⁹ Epi Info TM is public domain software statistical software for epidemiological use developed by the Centre of Disease Control (CDC) and can be downloaded from <http://www.cdc.gov/epiinfo>.

As already identified in the conceptual framework based on Russell (2004:148), there are key themes such as access (transport), insurance, quality of care, coping strategies such as borrowing and impact on livelihoods (assets, income and food security) that this study will seek to investigate, measure and describe. As such, thematic analysis is thus *fait accompli* because of its flexibility as it is not necessarily that the themes are apparent in the data, but can be created by the researcher in the manner that they understand and interpret the data at hand as Ely et al (1997:205-6) note. The rationale for choosing this method over other qualitative data analysis methods such as Interpretative Phenomenological Approach (IPA) Grounded Theory, Discourse Analysis, Ethnography and Narrative Analysis is based on the following considerations:

- The focus of this study is not to find out the meaning the PLWH attach to their treatment seeking behaviours. An Interpretative Phenomenological Approach (IPA) would have been relevant. Smith (1996:264) outlines IPA as follows: "*The aim of IPA is to explore the participant's view of the world and to adopt, as far as is possible, an 'insider's perspective'*" (Conrad, 1987) *of the phenomenon under study*. However, IPA has shortfalls in that it does not identify themes about the factors influencing treatment seeking behaviour and their effect on out of pocket payments.
- Grounded theory would have been appropriate if the research question was to generate theory based data to explain the phenomenon under study (Legewie/Shervier- Legewie, 2004). Grounded theory would have sought to understand the process through which PLWH learn to cope or manage out of pocket payments in order suggest or test a hypothesis.
- Discourse analysis approach would have been relevant if the purpose was to identify and understand the ideologies of treatment seeking behaviour. It is based on the constructive role of language in social reality (Sinclair and Coulthard 1975, Van Dijk 1985, Potter and Wetherell 1987, Fairclough 1995, Gill 1996, Titscher et. al. 2000).
- Ethnography would have been more appropriate to understanding the culture and historical context of the treatment seeking behaviour of PLWH, but this study is not looking at this. According to Chase (2005) a narrative can refer to the life history of a person interviewed, a story about a significant aspect of their life, or a specific event.
- The purpose of the study was not to pull our data apart to get at essences, so as to gain valuable insights by putting the data back together so as to tell a story from the viewpoints of different participants as narrative analysis would have required.

4.6 Recruitment

Several strategies were used to maximise participant recruitment including working with PLWH who were invited through civil society organisations that formally work with them such as the Zimbabwe HIV/AIDS Activist Union Community Trust (ZHAAUCT), Zimbabwe Network of People living

Positively with HIV (ZNPP+), Women AIDS Support Network (WASN), Life Empowerment and Support Organisation (LESO) and the National AIDS Council across the 12 districts and 94 wards under 4 local Authorities namely Epworth Local Board, Ruwa Local Board, Chitungwiza Local Authority and Harare City Council.

Most of the participants recruited were from existing support groups, who indicated they were available to be interviewed. The nature of the research objectives and questions were relevant factors in considering which questions to ask the respondents. The first part of the study was quantitative; although it was meant to provide a general picture of how much was spent by PLWH on treatment and treatment seeking behaviour. This allowed for a more detailed investigation into why these out of pocket payments were made. In summary the following data collection steps were observed:

- 1 A sampling frame based on PLWH in Harare Metropolitan Province in the year 2012, was obtained from the National AIDS Council.
- 2 A sample was identified to which questionnaires would be administered to find out the rate and type of out of pocket payments made. This sample of 383 (considering a response rate of 1) was based on those 88,462 adult patients currently on ART in the Harare Metropolitan Province (NAC, 2011) across 12 districts and 94 wards under 4 local Authorities namely Epworth Local Board, Ruwa Local Board, Chitungwiza Local Authority and Harare City Council (NAC2011:7).
- 3 A questionnaire was developed based on the literature. The researcher obtained a list of support groups from the National AIDS Council and organisations working with People living with HIV focal persons in organisations working with PLWH. The researcher sought for permission; to find out if they would be willing to administer the questionnaire on his behalf as they were already known and working with PLWH.

4.7 Ethical considerations

Although this study was based in the Harare Metropolitan Province, ethical approval was obtained to undertake research at macro level. At this level approval was granted in February 2013 by the Medical Research Council of Zimbabwe (MRCZ) which is the national controlling body that regulates all health related research in Zimbabwe (See Annex 1). The key ethical issues in this project are informed consent, the participant's confidentiality and data protection, are according to good clinical practice guidelines. Research ethics "*are guidelines that safeguard against any harm and protect the rights of human beings in research*". (Rogers 2008). All the participants in the study received information packs which described the purpose of the research and why they were selected to participate. They included consent forms. The study participants had the right to withdraw from the research and this was made explicit on the information sheet and verbally reiterated at the time of the data collection

process. The consent forms were available in English and translated into Shona which is the predominant local language in Harare Metropolitan Province according to Chimhundu (1993).

4.8 Minimising biases

It is difficult to completely avoid bias in any research. In attempting to remove one form of bias another may inadvertently be introduced. As pointed out by Sayer (2000:33), knowledge is a product of both intra-discursive and referential relations. As such, this view recognises that the knower's history, culture, interests and experience inevitably enter into all forms of knowledge production. However, Last (1988) stresses that bias is a form of systematic error that can affect scientific investigations and distort the measurement process. A biased study will lose validity in relation to the degree of apparent bias. Therefore, the goal of any researcher is to minimise bias. Sackett (1979) reported as many as 35 different biases which can affect research. For this study, the researcher guarded against four broad classes of bias as identified from Sackett's (1979) list tabulated below:

Table 1: Type and causes of biases

Type of Bias	Causes	Example
Selection or exclusion	Caused by how the sample is selected or identified	In the quantitative part most of the respondents belonged to PLWH such as the Zimbabwe HIV/AIDS Activist Union Community Trust (ZHAAUCT), Zimbabwe Network of People living Positively with HIV (ZNPP+), Women AIDS Support Network (WASN), Life Empowerment and Support Organisation (LESO) and the National AIDS Council. To ensure other groups that were smaller were included, such as the Love Foundation and Tafara AIDS and Arts Foundation (TAAF) the researcher used the national register of HIV organisations at the National AIDS council to identify these and other smaller groups.
Sample	Caused by the type of sampling method used	The sample in both the quantitative and qualitative parts of the study tended to be those willing to be part of the study. In some of the qualitative interviews the respondents were usually willing to speak openly about their condition and usually knew of others in a similar situation that the researcher could be referred to. The research assistants were encouraged to approach other networks of people living with HIV and encourage them to be part of the sample.
Interviewer	Subconsciously or	The fact that questionnaires were being administered by someone who was living with HIV and sometimes known to the respondent affected

	unconsciously caused by interviewer non-verbal or verbal communication cues.	<p>the way they responded to the questionnaire questions.</p> <p>In the qualitative interviews the interviewer was seen as an outsider and the way that the respondents answered sometimes required that the questions be reinforced with another subset of questions.</p> <p>The researcher tried to build rapport with the respondents to gain mutual trust.</p>
Recall	Inability by the respondent to provide information due to inability to recall.	<p>Where the respondents were asked a date when they started treatment, and had to pay for services they sometimes mixed the dates.</p> <p>This bias was minimised by giving participants enough time to consult relevant documentation including medication labels, where necessary.</p> <p>Returning to ask the same question for which data was not immediately available at a later date when that data would have been located.</p> <p>In some case this required the researcher to ask the same question later so as to establish the dates.</p>
Language	The language used also tended to influence the way the questions were answered.	<p>Sometimes slang and colloquial language indirectly referring to HIV/AIDS conditions are used rather than direct descriptions.</p> <p>To ensure the correct response was obtained instead of direct questions slang and colloquial language indirectly referring to HIV/AIDS conditions was used.</p>

4.9 Pilot study

The data collection instruments were tested and modified in order to ensure that they were able to elicit the required responses and to remove those questions that proved difficult or embarrassing to the respondent. It also provided an opportunity for the researcher to practice data analysis including the feasibility of using electronic software for qualitative data analysis. The pilot also helped to test the appropriateness of the coding frame.

After transcription, the responses were grouped into major themes based on those developed by Russell (2004), McIntyre et al (2011) and Kagee et al (2011) viz treatment seeking behaviour, economical, burden of illness and impact on households. The categories and codes themes developed as tabulated below are based on the literature in chapter three:

Table 2: Coding framework for Treatment seeking behaviour and economic burden of illness

Codes	Categories	Theme
Stigma Religion Traditional Beliefs Waiting time Family and friends Stock out of commodities Quality of care Willingness to pay Need to minimise property loss	Socio-cultural	Treatment seeking behaviour
Treatment Diagnostic tests User fees Transport Health insurance	Direct cost/OPPs	Economic burden of illness
Borrowing Selling assets	Coping strategies	
Traditional healers Transactional sex work Periodic defaulting Self-treatment Forced to work instead of school	Poverty & food insecurity	Impact on households

4.10 Reliability

After the data analysis was completed the researcher shared the qualitative findings with the respondents to enable them to verify and comment.

4.11 Conclusion

This Chapter has spelt out the research design and its justification, the sampling methods, data collection methods and processes and data analysis procedures to be followed. A descriptive study design using both quantitative and qualitative techniques has been explained. The rationale behind the choice of data collection methods (quantitative and qualitative) and steps taken to minimise bias have been described. A description of the methods used to analyse both quantitative and qualitative data is provided including a brief on why the key informant interviews were used instead of focus group discussions to solicit treatment seeking behaviour and their effects on out of pocket payment and impact on livelihood. The ethical considerations and procedures that had to be fulfilled before the study commenced have also been proved. A pilot study was undertaken to pretext and refine the data collection instrument. The next chapter presents the findings or emergent issues which are presented according to the direct and indirect costs based on Russell's (2004) conceptual framework and augmented in part by a sub analytical framework that uses Kagee et al (2011) socio cultural factors to influence treatment seeking behaviour.

Chapter Five: The findings

5.1 Introduction

In an endeavour to provide a clear and coherent story, this chapter seeks to present data both quantitatively and qualitatively that tells a story of how much PLWH are paying for their treatment. The chapter focuses on why this is the case and how it has affected their livelihoods. This story will be told in two parts; the first being the quantitative section and the second being the qualitative section. The quantitative section presents data that tells us the number and services paid for, including the amounts; whether these amounts can be deemed catastrophic based on proportion spent on intervention in relation to the household income.

The second part of the results which are qualitative tell a story that complements the quantitative data above which has presented the direct costs and treatment seeking behaviour patterns which made households to:

- a. Adopt treatment seeking behaviour influenced by socio-cultural factors due to stigma, religious belief, concern and pressure from family and friends, willingness to pay and the need to minimise losses. These factors contributed towards households;
- b. Adopt coping strategies such as borrowing and selling an asset for hardship financing;
- c. In some instances suffering consequences in the form of deprivation of physiological needs and budgetary constraints.
- d. Fail to be resilient enough, resulting in further impoverishment. Households made use of traditional medicine, transactional sex, periodic defaulting on medication, proliferation of self-treatment, and were subject to continual suffering from multiple infections and work for treatment by young people.

5.2 Descriptive quantitative results

In this part of the quantitative analysis the story that unfolds is that of where PLWH seek services, the treatment seeking behaviour patterns; the direct costs/OPPs associated with these treatment behaviour seeking patterns which impacted on the average income of households resulting in them adopting coping strategies.

5.2.1 Treatment seeking behaviour patterns

In this section the story revolves around table three that seeks to illustrate the treatment seeking behaviour and direct costs. More specifically the table 3 below shows the services provided by provider type, the number that used the provider and the average cost pertaining to the services offered by the health provider. From the table below, it can be noted that 25.3% of the study population sought services from private laboratories and diagnostic centres, followed by private pharmacies at 22.7%, council clinic (18%), private clinics (17%), government hospitals (13.6%) and

mission/NGO health facilities (3.4%) in terms of use of services. However in terms of costs, most of these occurred at private laboratories and diagnostic centres with the least costs being at mission/NGO health centres. The qualitative analysis should be able to provide an explanation as to why this was the case and yet the cost of treatment is higher in private clinics, laboratories and diagnostic centres.

Table 3: Treatment behaviour seeking patterns, payment by type of health service and provider

Type of treatment service provider	Number or percentage that paid for treatment related services by provider													
	Number or percentage that visited type of treatment service provider		Number or percentage that paid for User/consultation fees [mean (sd)] (± 10.48)		Number or percentage that paid for transport to access treatment service [mean(sd)] (± 0.04)		Number or percentage that paid for (ARVs) [mean(sd)] (± 1.52)		Number or percentage that paid for antibiotics [mean(sd)](± 3.12)		Number or percentage that paid for to have a CD4 Count test done [mean(sd)] (± 5.92)		Number or percentage that paid for other diagnostic tests [mean(sd)] (± 3.56)	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Government hospital	52	14	5	1.7	1	0.4	0	0	0	0	20	5.5	20	28
Council Clinic	69	18	1	0.3	0	0	0	0	0	0	20	5.5	20	28
Mission hospital/NGO health centre	13	3	0	0	5	2.0	0	0	0	0	0	0	0	0
Private laboratory & diagnostic centres	97	25	0	0	1	0.4	0	0	0	0	40	11	40	56
Private clinic including traditional healer	65	18	22	7.3	1	0.4	0	0	0	0	0	0	0	0
Private pharmacy	87	23	0	0	1	0.4	50	0	3	5.6	0	0	0	0
Total number or percentage that reported paying for any type of treatment related service.	n=383 or 100%		n=301 or 78.6%		n=241 or 62.9%		n=312 or 81.4%		n=54 or 14.1%		n=367 or 95.8%		n=71 or 18.5%	

Chi-Square =2.13, p-value =0.322

5.2.2 Direct cost of treatment seeking behaviour

5.2.2.1 User fees

Overall, 78.6% of the study population paid user fees for HIV related treatment. While the government policy explicitly exempts those with HIV from paying user fees, the results herein tell a different story. It can be noted from the table that it was only at mission/NGO health facilities that PLWH paid nothing, but paid USD5 at government hospitals and USD1 at council or municipal clinics and USD22 at private clinics. This also explains the high cost variation [mean (sd)] (± 10.48)

5.2.2.2 Transport costs

The cost of transport according to the findings of this study was USD1, except for when services were sought from mission/NGO health facilities. These facilities are located and directed towards providing treatment and health services in general for the rural or peri-urban populations. 62.9% of the study population however paid for transport towards accessing health services (treatment and or diagnostics).

5.2.2.3 Treatment costs (ARVs)

ARVs are supposed to be provided freely in all public health facilities, however this study shows that 81.5% of the study population paid for ARVs, mostly purchased from private pharmacies at an average price of USD50 the qualitative results will clarify why PLWH opted to go to a private provider and incur higher costs.

5.2.2.4 Treatment costs (other i.e. antibiotics)

It was necessary to include the cost of antibiotics. For example Cotrimoxazole is normally given together with ARVs and is supposed to be for free. In addition other antibiotics are required to ward off infections. While there was no charge for these in public and mission/NGO health facilities, most pharmacies charge USD2-3 for a 30 day course of Cotrimoxazole.

5.2.2.5 Diagnostic tests costs (CD4 Count)

95.8% of the study population paid towards having a CD4 count test done. Although the cost was cheaper in the public health facilities such as government hospitals and council clinics and were free at mission/NGO health centres most of the study population used private laboratories and diagnostics centres, the qualitative analysis will explain why this was the case.

It also needs to be noted that, owing to the horizontal linkages that exist between private clinics, private laboratory and diagnostic centres, the cost can be high.

5.2.2.6 Other Diagnostic tests

In addition to having a CD4 count test done, other tests that could be required include a CD8 count and a full blood count. While about 18.5% of the study population paid for these services, it would be necessary to find out why this was the case.

Having had an overview of the treatment patterns and the direct costs associated with treatment, it is necessary to have an overview of how these costs impacted on average household income.

5.2.3 Impact of direct cost/OPP on average house hold income

The impact of the direct cost of services on the average household income is shown in table below, which indicates that by service cost, transport was generally less than 1% of average household income. 6.3% of the average monthly income of households was paid as user fees in private clinics. In public health facilities such as government hospitals and council clinics the user fee as direct cost was less than 3% and was not charged in mission/NGO health facilities. Antiretroviral drugs were free in all facilities except in private pharmacies where the cost was 14% of the average monthly household income. The cost of diagnostic tests was free in mission/NGO health centres but was less than 6% in public health centres such as government hospitals and council clinics yet in private laboratories and diagnostic centres the cost was 11% of average household income at the point of need.

Table 4: Impact of direct health costs on household income

Type of treatment service provider	Average service cost in USD/ Average monthly household income (USD350) ³⁰													
	Visit by service provider		Average user/ consultation fee / Average household income		Average transport cost / Average household income		Average cost of treatment (ARVs) / Average household income		Average cost of antibiotics / Average household income		Average CD4 Count test / Average household income		Average cost for other tests / Average household income	
	No.	%	usd	%	usd	%	usd	%	usd	%	usd	%	usd	%
Government hospital	52	13.6	5	1.4	1	0.3	0	0.0	0	0.0	20	5.7	20	5.7
Council Clinic	69	18	1	0.3	1	0.3	0	0.0	0	0.0	20	5.7	20	5.7
Mission hospital/NGO health centre	13	3.4	0	0.0	5	1.4	0	0.0	0	0.0	0	0.0	0	0.0
Private laboratory & diagnostic centres	97	25.3	0	0.0	1	0.3	0	0.0	0	0.0	40	11.4	40	11.4
Private clinic including traditional healer	65	18	22	6.3	1	0.3	0	0.0	0	0.0	0	0.0	0	0.0
Private pharmacy	87	22.7	0	0.0	1	0.3	50	14.3	3	0.9	0	2.9	0	0.0
Total number or percentage that reported paying for any type of treatment related service and portion of income spent.	n=383		n=301 or 78.6%		n=241 or 62.9%		n=312 or 81.4%		n=54 or 14.1%		n=367 or 95.8%		n=71 or 18.5%	

³⁰Based on average income per-month of a household (PICES, 2011/12:79).

In concluding this section it needs to be pointed out that the literature (Pradhan and Prescott , 2002; Xu et al, 2007; Wagstaff and van Doorslaer, 2003; Russell, 2004; van Doorslaer et al., 2007; Sakesena et al,2010) indicates that expenditures on health are catastrophic if they are above the range of 10% or more of household expenditure. Doorslaer et al (2006) and Mendola et al (2007:5) have argued for a range of 0.05% for Asian countries and 2.8% for 5 Eastern European countries or using the World Bank poverty line of USD1/day for Asia and USD2/day for the five European countries.

5.2.4 Coping strategies

Coping strategies were adopted to mitigate the effects of direct costs of treatment and or for paying towards treatment seeking behaviour patterns.

5.2.4.1 Borrowing

In this section a synopsis of the reasons for borrowing money and what type of services were paid for out of pocket is given. From table 5 below it can be seen that borrowing was used as a source of hardship financing by a total of 353 or 92% of the study respondents for direct costs of treatment and diagnostic seeking behaviour. The reasons given by the respondents for borrowing were to meet the costs of treatment n=113 or 30% of the respondents, transport costs by n=84 or 20% of the respondents, user fees was cited by n=78 or 22% of the respondents, laboratory costs by n=62 or 16% of the respondents while 4.2% or n=16 cited the need to pay for other tests as the reason they borrowed.

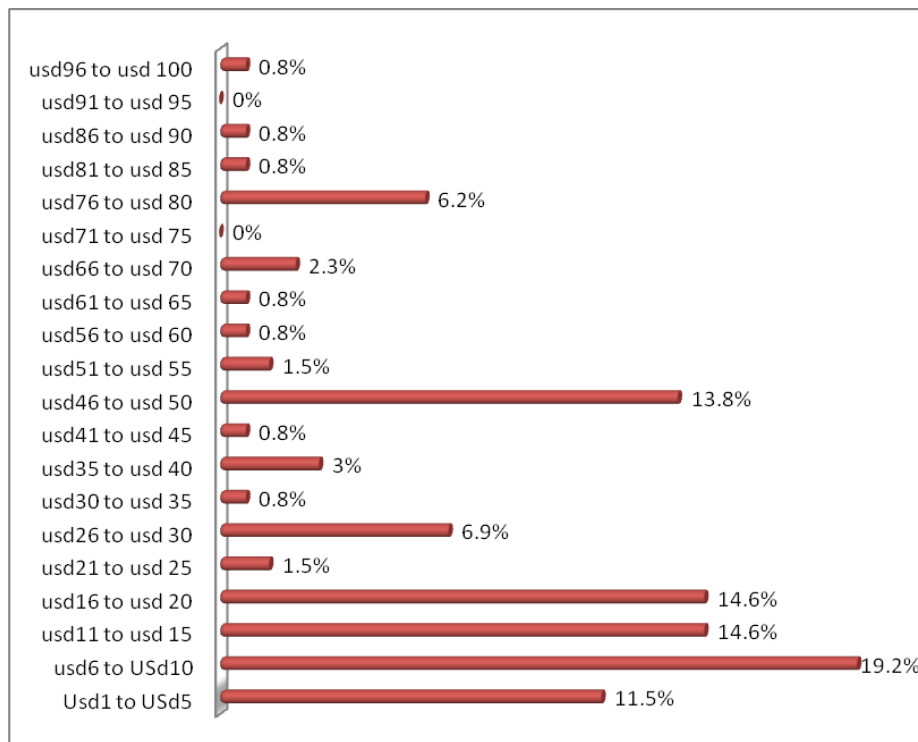
Table 5: Total of study population that borrowed to pay for treatment related costs

Total number who borrowed n=353 out of 383 or 92.2%	Number of study population who paid for treatment related direct costs by type of service									
	Treatment		Laboratory		User/consultation fees		Transport		Other tests	
	Number	%	Number	%	Number	%	Number	%	Number	%
	n=113	29.5%	n=62	16.2%	n=84	21.9%	n=78	20.4%	n=16	4.2%

Chi-square = 7.89, p-value =0.023

The graph below illustrates the amount that was borrowed. Which shows that most of the amounts ranged between USD11 to 20 by 29.2% of the respondents while, 19.2% borrowed between USD6-10; 13.8% between USD46-50, 11.5% between USD1 to 5. Others that borrowed beyond these amounts are 13.8% for amounts between 46 to 50, 6.9% for amounts between USD26 to 30 and 6.2% for amounts ranging between USD76 to 80.

Figure 6: Amount borrowed by percentage



5.2.4.2 Selling an asset

According to table 6 below the reasons given by the respondents (n=284) for selling an asset as part of hardship financing was to pay for costs associated with treatment and diagnostic seeking behaviour. Treatment according to n= 104 or 27% of the respondents was the reason for selling an asset, 26% of the respondents cited Laboratory associated costs; while n=37 or 9.7% sold an asset to pay for user fees with 9.1% attributing the need to undergo other tests.

Table 6: Total of study population that sold an asset to off-set health related costs

Total who sold an asset n=284 out of 383 or 74.1%	Number of study population who paid for treatment related direct costs by type of service									
	Treatment		Laboratory		User/consultation fees		Transport		Other tests	
	Number	%	Number	%	Number	%	Number	%	Number	%
	n=104	27.2%	n=98	25.6%	n=37	9.7%	n=10	2.6%	n=35	9.1%

Chi-square = 7.89, p-value =0.023

The nature of assets sold is shown below, the purpose is to provide an indication of the type of asset sold and the number that sold this type of asset. The sale of assets has been linked in the literature to be contributing towards poverty especially those that facilitate economic and social reproduction such as trade or production. But more importantly the sale of assets erodes the households' ability to accumulate capital and be able to shape their environment for the better.

Table 7: Type of asset sold by number and percentage by study population

Type of Asset	Frequency	%
Bed and kitchen unit	1	0.4
Bicycle, stove and plates	7	2.5
Car	1	0.4
Cattle	1	0.4
Cattle and 2 bags of maize	1	0.4
Cell-phone	73	25.7
Clothes	42	14.8
Cart or wheel barrow	16	5.6
Display Unit	1	0.4
Food	2	0.7
Fridge	37	13.0
Fridge, DVD and radio	4	1.4
Home theatre and DVD	1	0.4
Land	8	2.8
Other livestock	7	2.5
Other livestock, sofas	1	0.4
Maize harvest	1	0.4
Radio	13	4.6
Radio, Television, pushing tray	1	0.4
Sewing machine	19	6.7
shoes	9	3.2
Sofas	3	1.1
Stove	13	4.6
Table and four chairs	4	1.4
Television and accessories(i,e DVD))	1	0.4
Wardrobe and Room divider	17	6.0
Total	284	100

What can be noted from the above table is that physiological means of survival such as food, livestock and clothes were sold to pay the direct costs/OPPs due to either treatment related seeking behaviour or

for treatment. In some cases, factors of production such as land were sold as a form of hardship financing to pay for either treatment or conditions associated with accessing it. The qualitative analysis will shed more light on how the sale of these assets either productive or necessary for social reproduction affected household livelihoods.

5.3 Qualitative results

5.3.1 Profile of respondents

Table 8: Characteristics of key informants n=16 (Male =9: Female = 7)

Name	Age	sex	Residential Area	Nature of Occupation	Marital status
Chamu	36	M	Harare	Kombi Driver	Married with 2 children
Ida	46	F	Chitungwiza	Teacher	Widow with 2 children
Ropa	54	F	Harare	Sub-editor	Single mother with 2 children
Edd	39	M	Ruwa	Self-employed ICT	Married with no children
Trust	38	M	Goromonzi	Unemployed	Married with 2 children
Passmore	41	M	Harare	Self-employed ICT	Married with 3 children
Gogo	55	F	Chitungwiza	Unemployed	Widow with 4 children and 2 grandchildren
Shungu	42	F	Harare	Property developer	Single parent with 2 children
Jim	33	M	Harare	Health Assistant	Single
Andrew	30	M	Harare	Self-employed mechanic	Married with 2 children
Sasha	26	F	Harare	Self-employed 2 nd hand clothes trader	Single parent with 2 children
Tendayi	38	M	Harare	Self-employed porter	Divorced with 2 children
Tariro	51	F	Chitungwiza	Unemployed	Mother of 4 children
Admire	40	M	Harare	Plumber	Married with 3 children
Almustafa	19	M	Harare	General hand	Single
Precious	21	F	Ruwa	Maid/Domestic worker	Single

5.3.2. Treatment seeking behaviour (TSB)

5.3.2.1 Socio-cultural factors

5.3.2.1.1 Stigma

From the study, it can be seen that stigma influenced the decision to pay out of pocket for treatment, in addition to other factors related to service delivery. In transcript 8; ‘Shungu’ cites privacy, in addition to stock outs and long queues as the objective basis upon which she decided to opt to buy her ARV’s out of pocket.

In transcript 3, ‘Ropa’ makes an observation in the context of the church, of a fellow congregant calling off a relationship because his partner was HIV positive. As elaborated in the interview transcript 3 below, the fear of being rejected and not being able to get married and have children, may also prompt one to consider paying out of pocket for treatment. A woman’s social standing in African society depends on her ability to bear children, as Batezat and Mwalo (1989) have argued. The fact that one is rejected and told they cannot have children can be devastating, as society expects a woman to be married and to procreate. This might force women to decide to opt to pay for treatment as a way of reducing the symptomatic manifestation of HIV. Their chances of getting married are enhanced as the interview extract below highlights.

Interview transcript 3 “Stigma, yes it exists.”

Researcher Is there stigma in your church?

Ropa Stigma, yes it still exists, like this girl I sent pictures of me before and after I started treatment. She was actually dating some guy who told her and insisted let’s go and have this test before we marry. She tested positive and the guy tested negative initially the guy was supportive blah. Then one day he just told her that ‘we cannot have children if you are HIV positive *etcetera*’ and that was quite devastating for this girl. I think sometimes people will have to be on ARVs bought privately so that their condition is not known.

Researcher What is the position of your church on those that are HIV positive?

Ropa The church does preach a lot about love and tolerance and the scriptures around that are always spoken about. In essence it’s fine but among the church goers I do not think they fully understand what these scriptures relate to. I have encountered cases of heart breaks, like the girl I spoke about who was asked by the boyfriend to go with him and have an HIV test.

In the transcript above it is also apparent that there appears to be a contradiction between the Christian faith, which is supposed to accept an individual as he/she is and the reality of HIV and stigma. It also shows the gap in locating HIV in the religious sphere, but also the broader societal lack of acceptance or denial, hence the shunning of people thought to be affected by HIV.

Interview transcript 8 “So I wouldn’t want to go to a public health facility.”

- Researcher What were your reasons for opting to buy the ARVs on your own?
- Shungu Plus the discretion, the stigma is still there. It hasn’t really changed. So I wouldn’t want to go to a public health facility I would want to do my own private thing.
- Researcher Where do you buy your ARVs?
- Shungu I get them from a private pharmacy. There is this lady who comes to our church who owns her own pharmacy, that’s where I purchase my own drugs and she is aware of my status and is very discreet so to speak.

The issue of lack of privacy is further reinforced by Jim in the interview transcript 9 and Ida in interview transcript 1 below when he describes being in a queue which according to him “...*have a lot of people; children and adults will all be in the same queue.*” This could force others, not keen to be seen in such queues to opt for private health providers at extra cost as Shungu captured above, who opt to pay for their own ARV’s.

Interview transcript 9 “Children and adults will all be in the same queue.”

- Researcher Describe these queues for me further?
- Jim The queues have a lot of people. So sometimes those who want to go to school are told to go in front of the queue, how about us who do not go to school, what do we do? All of us will be in the same queue regardless of how early one would have been there waiting, but those in school uniforms are allowed to go in front of the queue even if they are late, so we have to wait for our turn.

The lack of privacy, that is epitomised in the interview transcript above, where school children are in the same queue for ARVs as adults can force others to rather pay out of pocket for their treatment.

In interview transcript 18: Ida also points to the lack of privacy as the objective basis for buying her treatment and also seeking diagnostic tests privately. The loss of self-esteem that comes with being in multiple queues is elaborated below.

Interview Transcript 18 “This put me off.”

Researcher Why do you buy your ARVs?

Ida I tried to get transferred to the public health scheme by my doctor. But my doctor preferred that I continue obtaining the ARVs from a source that was reliable. The other reasons are that, the queues at the public health facility which my sister had recommended are long, this put me off. The other reason is that, the health staff keeps a register of their OI patients if you are not registered with them they will attend to you after they have completed attending to their own OI patients in their register. Some time they will not even attend to you.

The staff has a tendency of shouting out and specifies the type of queue you need to be in for example those coming for general health conditions are told to be in one queue. Those requiring to HIV medication in another queue and pregnant or lactating mothers in yet another queue so you end up with three types of queues. It can be embarrassing, to stand and wait in the queue for those with HIV as most people in the other queues will be look at you as if you are cursed or something.

This affects your self-esteem. Imagine going through this process every month? Patients in other queues will know the purpose of why you have come to seek treatment and the stigma and discrimination that comes with being HIV positive ends up affecting you, as many people will know your status and may even begin to gossip about it.

So, I prefer the services of my private doctor as I will have the privacy of no one knowing what I am there for.

This is due to the fact that, adults would not want to be subjects of gossip. Stigma in the case of Jim in interview transcript 9 below makes him to pay out of pocket for his supply of ARVs since losing weight may be associated with HIV, and give rise to gossip about one's condition. The fear of rejection by friends and society necessitates the need to seek immediate treatment which in this case means having to pay out of pocket expenses for treatment to avoid looking sick due to weight loss. The fear of stigma both 'felt' and 'enacted' as Scambler (2004) has observed, can cause one to be conscious of their appearance, and in their endeavour not to appear 'thin' one is forced to pay out of pocket for treatment. This issue comes out in interview transcript 9, where Jim notes that '*When you begin to lose weight, it will be the first thing that people will notice... I will have to buy the pills to avoid defaulting and getting very sick*'.

Interview transcript 9 “People will notice this weight loss.”

Researcher What makes you afraid of defaulting?
Jim The most important thing is, one, not many people know I have this disease. Most people around society do not know this. When you begin to lose weight it will be the first thing that people will notice. For now no one can tell I am on pills, but if I begin to lose weight people will notice this weight loss and begin to think my days on earth are few and numbered.

In public health institutions patients coming for non HIV related treatment do not share the same queues as those on ART. This makes patients on ART feel that their health condition will be disclosed beyond the health facility. This stigma is societal and self-caused by being reluctant to be seen taking ARV's, which are associated with being HIV positive. This causes one to decide to pay out of pocket for ARV's, usually from a private source. The issue of stigma manifests in the church too.

5.3.2.1.2 Religious beliefs

Religion tends to stigmatise and attach blame to HIV, as highlighted in Deribe et al (2008), Hutchinson et al (2007) and Medley et al. (2004). According to Epstein (2007), Genrich et al (2004) and Quinn et al (1986) HIV transmission in Southern Africa is predominately sexual, which arouses moral condemnation and stigma. At the same time, the church is seen by PLWH as providing psycho-social support (spiritual counselling and prayer support) material assistance in times of being bedridden due to illness, or support during bereavement as Dilger (2007) documents. There is the case of HIV being seen as a way of God punishing a person, as Hess et al (2007) discovered in a study undertaken in Gambia. Prayer and faith in God was also cited by Genrich et al (2004) as a way of preparing for and accepting death. In a study of African American PLWH communities in the United States, Cotton et al (2006) and Pargament (2004) also found that religion was a way of coping with HIV and AIDS. Anderson et al (2009) make similar inferences from a study done in London, that religion was a way of coping with anxiety and depression among black African men and women in the United Kingdom.

In interview transcript 8 below, Shungu once again reiterates the association of HIV with promiscuity in the church when she notes '*usually this disease is tagged with promiscuity.*' But what becomes evident is how religious beliefs can, on one hand, make congregants stop taking life-saving medication when she observes '*she decided to stop taking ARVs and believed that faith would cure her*'. On the other, congregants may take ARVs quietly, even if it means they go to private pharmacies. While in the same interview she points out that the pastors do not encourage church members to stop taking medication because of religion. She notes she would continue paying for her treatment as prayer was working through these 'tablets,' and she did not want to be like one of the elder's wives who died when they stopped taking ARVs. Perhaps this could be due to the negative rumours which are associated with taking ARVs.

At the extreme, in a study done in Uganda Wanyama (2007) argues that belief in prayer was seen as being able to cure HIV and make ARVs unnecessary. In interview transcript 3; religion seems to be in denial about HIV and AIDS and attribute it to a '*demon etcetera etcetera*' which could have influenced her to stop treatment.

Interview transcript 8 "sickness is a demon."

Researcher How is stigma addressed in your Church?

Shungu It's there. To be quite honest it's there! People are judgemental you see the small things that happen in church when somebody who was very well up goes broke and all there is a lot of talk that goes on, what's more when sickness comes on an individual. It depends on the type of sickness you know usually this disease is tagged with promiscuity, so to speak. I have been in this church for twenty years, the stigma is there, there is a lot of discrimination and people will start to think what is going on in your life, how you got it? Why you got it? And things like that, I do not really think at this point in time it is going away. Maybe, we will get there but not at this point in time stigma is there. So others take ARV's quietly even if they have to go to private pharmacies for this, and would not want to be associated with being promiscuous.

The interview extract above resonates with some of the phenomenological literature regarding the way stigma affects those with chronic ill health, as shown by Burton (2000), Knight, Wykes and Hayward (2003). Shungu goes further to suggest that church members would rather pay out of pocket in private pharmacies rather than be seen at a public health facility seeking ART. This would reduce the chances of them being seen by other members of her church. From the interview extract above, there is apprehension about being seen to be taking ARVs. This could also be a case of what Jones (2009) points out, stigma is transferred from HIV to ARVs.

To counterpoise the religious beliefs rooted in Christianity, a look at how traditional belief systems work in the context of HIV and AIDS is also important, as it is informative regarding how these beliefs provide the basis on how and why people pay out of pocket for treatment. Zou et al (2009) found out that religious beliefs can result in passive resignation and affect treatment adherence "*I believe that if a person has HIV/AIDS most treatment will not change anything*" cited in Hess et al (2007). Belief in traditional medicine and faith healing is widespread and seems to be reaffirmed from the following extracts of the transcripts from interview 4 and 2: Sow (1980:51) asserts that in the mind of the traditional African, in order to understand the causes of ill-health it was important to know the "why" and "who?" of the illness. Van Dyk (2001) argues that the ascription of HIV to witches and sorcerers alleviates anxiety and feelings of guilt. It provides people affected by HIV with

the means with which to impose meaning on things that cannot be explained by the bio-scientific knowledge.

Interview transcript 4 “How she picked this up... I do not know.”

Researcher Can you describe how the traditional healer assisted you?

Edd When I got to this traditional healer, he looked at me and said I was not well and was taking too many tablets to cure this devastating disease. How she just picked this up to just say I know you are taking pills, by just looking at me I do not know.

It also appears that the traditional healer is revered, as Edd states “*how she just picked this up to just say I know you are taking pills, by just looking at me I do not know*”. What may have affected Edd’s decision in part to pay for traditional medicine rather than continue with ‘western medicine’ was this perceived psychic prowess of traditional medicines over the virus.

However, the faith in traditional beliefs can be broken, which, as described in the interview below locates HIV in traditional medicine as being associated with ‘spirit about to emerge’ ‘bewitchment’ ‘ancestral spirits’, when no immediate observable health outcomes are forthcoming. In the interview transcript 3 below, Gogo decides to seek conventional treatment after her health shows no signs of improving. But not until her livestock had been decimated

Interview transcript 2 “I was bewitched.”

Researcher Have you been to prophets or traditional healers?

Gogo I went to N’anga’s some of whom demanded my livestock until I had none left and Maprofeta (prophets³¹) but nothing in my health changed. I was told that I had been fixed, I was bewitched, and others said it had to do with my ancestors, I had a spirit which wanted to emerge through me, and they said whatever they wanted. But when I started going to the hospital to get tested and was found to be HIV positive I accepted my status. Once I accepted my status, I started taking ARVs and my health changed and my body felt better.

5.3.2.1.3 Concern and pressure from family and friends (social networks)

In this section we explore how family and friends played an important role in making decisions on whether to start on ART and its related out of pocket costs. More specifically, it looks at the role that family and friends make in relation to the interviewee deciding to get better even if it means paying for it. Through the support of family and friends uptake and adherence to the medical regimen can be improved, as noted by Fennell et al (1994), Hart et al (1990), Stuart and Davies (1972). Bangura (1997) and Hogben and Byrne (1998) argue that the environment that surrounds human beings

³¹ Prophets refers to the apostolic sect who normally do not encourage their members to take or use conventional medicine.

influence them in decisions they make. Friends also help to make decisions on the form of treatment or alternatives to take, as highlighted in the extract from transcript 8, 3, 5 and 6. The following in-depth interviews show these aspects of family members and friends influencing decisions on type of treatment. In transcript 8 the family expressed the desire of individual members to be a grandparent one day, and this influenced Shungu to want to stay alive. The means towards realising this wish was to be on ART, no matter the cost it required, as she states:

Interview transcript 8 “I want to survive; I want to see my grandchildren.”

Researcher What has motivated you to be able to buy your own ART?

Shungu I want to survive; I want to see my grandchildren (laughter). It’s about having the oomph for life to be able to survive. It’s not a death sentence it’s just a condition that I have. I have come to terms with that I want to make sure my life is prolonged in the processes.

Researcher Why do you think it is important to prolong your life?

Shungu It’s about wanting to be a grandparent and living life to the fullest. There is no sad thing having a lot of people suffering from a lot of issues where they do not want to take any medication, the fear of stigma, the fear of denial so to speak but as far as I am concerned I love my life and I want to make sure that whatever time the Lord decides to take me it’s not because I decided not to take any medication at whatever cost.

Interview transcript 3 “It was my Sister’s plea.”

The emotional appeal by a sister seemed to have galvanised Ropa to take action on her deteriorating health, as she says she did not want to let down her sister.

Researcher How long have you been unwell for?

Ropa If I look back I must have been sick for the past fifteen years because I remember when my sister sent me a message on my phone saying ‘I want my big sister back’. Big as in big because I was getting smaller and smaller I was losing weight and I thought it was diabetes that was making me lose weight even my daughter could tell there was something wrong, so when I told her I was HIV positive she wasn’t surprised. I had prepared her for this kind of news but to my youngest son it was devastating. In a way what they sent me touched me and I had to do something about my health and weight loss even if it meant paying for the treatment and I felt I could not let down my sister and daughter. I had to live because two of my children who are not in Zimbabwe and the youngest was rather scared she wanted to leave University to come and take care of me because relatives would call telling my children come and

look after your mother blah blah blah.

Death has to be located in the broader paradigm of the discounted cost of HIV, which is premised on social protection at a micro-economic level. A delay in death due to being on treatment provides societal benefits such as continual parental support, reduction in orphans. This also reduces income shocks that force households to have children working or creating street children, a situation that has been documented by Bandara et al (2014). It is this fear of dying and the consequences that influence the decision to pay for treatment. In this regard, there is a concern for leaving without both or one parent, and the responsibility of ensuring their survival. As the following in-depth interview transcripts extracts from Ropa (above), Trust and Passmore (below) bring out the issues of having to leave children behind. The need to provide as much parental support as possible comes out as the cause to be on treatment, even if it meant paying for it. This concern is for the need for investing in their off-spring through continual parental support, education and care. Trust articulates this firmly when he states the reason why he would like to prolong his life by being on treatment and paying for it as *'If you can be able to die later, you would have pushed the children in the meantime to grow while you would be still be alive and take care of them to the best of your ability as a family'*. The vulnerability of children in the two narratives plays a significant role in decisions on whether to pay out of pocket or not. Foster and Williamson (2000) noted that the death of parents has a great effect on children's lives. Ainsworth and Semali (2000), Poulter (1997), Semali and Ainsworth (1995) argue that, with the loss of one or both parents, a child becomes vulnerable, due to reduced financial support, which leads to food insecurity. In addition, this increases the social opportunity cost of the necessary psycho-social support and safety nets.

Interview transcript 5 "You do it for the Children."

Researcher What motivated you to pay for this treatment?

Trust When I went to the hospital that's when they said I should go and be tested and when I was tested I was found to be with HIV. The other thing was I knew it was the disease. I saw that if I do not enrol on the programme to collect pills I would die, I was afraid of dying.

Researcher What about death?

Trust Family now. Children. You do it for the Children you do not want to die it is a painful thing. If you can be able to die later, you would have pushed the children in the meantime to grow while you would be still alive and take care of them to the best of your ability as a family.

Interview transcript 6 “If I went down my family will not have any one to look after them.”

Researcher Why did you feel it was important to protect yourself?

Passmore The thing that made me join the ART programme was the need to extend my days of survival. In adding to my days it has to do with me being able to look after my family. I looked at this issue this way that if I went down my family will not have any one to look after them. So it was better for me to begin ART so that I can continue to look after my family.

5.3.2.1.4 Willingness to pay

In some instances respondents described how they were willing to pay to access health services in the hope of avoiding a delay in treatment. Shungu (below) describes how the side effects of being on medication have affected her, as she has to wake up at midnight to take her medication. However despite these setbacks, she is willing to pay for her treatment out of pocket as it is expedient for her.

Interview transcript 8 “Well I can afford it.”

Researcher Is paying for the ART and related services a challenge?

Shungu Well I can afford it. I do not really have problems financially as far as the drug is concerned. I am not saying everything is well. As far as the drugs are concerned I can afford to buy on my own. Business has been slow in the past months but here and there you make a sale or develop something.

Researcher What laboratory tests were done?

Shungu I went to a laboratory, I think it's on the first floor...No its not clinical laboratory but anyway I cannot remember the name my doctor asked me to go to. I had a CD4, CD8 and full blood count done. I paid for these tests, it was not a problem.

Researcher Did you have a liver function test done?

Shungu No, but I am due tomorrow for another set of CD4, CD8 and full blood count and then they will be able to tell me if the drug is still able to suppress the virus.

Researcher Do you pay on your own for these diagnostic tests?

Shungu Again, I will pay for these tests as it is important to see if the drugs are working fine.

This also is the point made by Ida interview 18, where she expresses her ability to pay for her treatment and diagnostic tests with a lot of support from remittances sent by her daughter and sisters in the diaspora. Without recourse to remittances from abroad, her chicken rearing project and vegetable enterprise, she would not have been able to manage on her teacher salary to seek the best possible health services and commodities as she concedes below.

Interview transcript 18 “The support from those in the Diaspora has been timely and effective.”

Researcher Why do you pay for your treatment?

Ida When I went to seek medical help that was when I was quite sick. My sisters in the diaspora sent money for me to go to a private doctor as my condition was rather desperate which required speedy attention. This could not have been provided in the public health facilities. Since then I have stuck to this doctor. He has been my doctor since I was taken ill and he treated me. Furthermore, my daughter who is also working in the diaspora assists as often as possible with treatment and diagnostic test costs.

Researcher How does payment for your treatment both ARVs and Laboratory tests affect your household budget?

Ida It does not. I get support from my daughter who ensures that I go for my regular reviews and get my ARVs from the chemist without fail. My sisters too in the diaspora chip in. I also rear and sell chickens and vegetables from my garden so I can safely say the cost of 25 dollars and the consultation and laboratory tests do not affect me as I can rely on any one of these sources of support. Especially the support from those in the diaspora has been timely and effective, as it is consistent and more than enough to pay my medical bills.

I also have chicken and vegetables from my garden for my food. My first born daughter has a good job and my last born son is about to complete school. My sisters and daughter in the diaspora make sure the fee and every other thing are taken care off. So the money I earn and the money from the selling of my produce is sufficient to see me through.

5.3.2.1.5 Need to minimise losses

Although the issue of stigma is very apparent in the narrative below; what seems to have stimulated Ropa to get well was the need to minimise loss of assets and perhaps begin recovering what had previously been stolen from her.

Interview transcript 3 “Paying for the most expensive drugs were better than losing property.”

Researcher Why did you make the difficult choice to pay for treatment?

Ropa I was HIV, I was sick they did not want me in their homes and I was basically a prisoner in my house. I remember at that time there was a woman who was brought in to look after me from Rusape and she stole so many things from me pots, plates, drinking glass, clothes, scarf's and many other things because she thought I would die and she was shocked when the police started calling her sometime this year because she has to answer for the things she stole from my home and the policeman who is investigating the matter says the first question the woman asked was is she still alive '*vachiri vapenyu here*'³². ...So whatever it took I had to get well even if it meant paying for the most expensive drugs it was better than losing property.

5.3.3 Health systems (waiting time, stock outs, perceived quality of drugs and absence of health insurance)

The section provides the health systems that influenced PLWH to make the difficult decision to spend more for health care or care at all such as queues, perceived quality of medication and the absence of health insurance. This resulted in PLWH treatment seeking services at a subsequent provider, the nature of the reasons for this is provided below in the following interview transcripts; as interview transcript 5 highlights the long waiting time and its associated opportunity cost, while interview transcripts 3 and 4 highlight the unavailability of stock and health insurance.

5.3.3.1 Waiting time

In most studies, waiting time is seen as a barrier to treatment as in Musheke et al (2013), Coetzee (2011), Hardon et al (2007). The ZHAAUCT (2014) note that at some provincial hospitals patients have to get up as early as 4am and queue if they are to be attended to. A study by Medicins San Frontiers (2007) notes that in Southern Africa inadequate infrastructure and shortages of health staff contribute towards long waiting times. In this study, the issue of waiting in the queue and not being certain as to when one would be served as well as the proliferation of various queues seems to put some of the interviewees off, and causes them to buy ARVs instead. Trust, in interview transcript 5, points this out when he says '*So I thought it was better for me to look for my own medicine.*' The inefficiency of the registration process was also a factor that contributed to the long queues. Issues of confidentiality are also important in this regard, as Trust further asserts '*I saw the queues, and they were asking for all sorts of things before they processed and gave you the ARVs.*' Again the issue of queuing is illustrated vividly when Edd points out in interview transcript 4 that '*You could go, there was a time people would spend a week there and not be served*'. Many of the people seeking services

³² Is she still alive?

are self-employed, and the opportunity cost of seeking treatment has to be juxtaposed to that of looking for money or waiting.

Interview transcript 5 “You spend the whole day without getting drug.”

Researcher Before buying your own drugs did you explore the possibilities of using other free public health facilities?

Trust Here in Harare, I only went once, I tried to enrol at Parirenyatwa³³ and stand in the line as well for me to also get medication. I just saw the queues, and they were asking for all sorts of things before they processed and gave you the ARV's. You can spend the whole day without getting any drugs, because the queue will be unthinkable. So you find that other people come without being assisted.

So I thought it was better for me to look for my own medicine, so that if I bought for half a month while in the meantime looking for money to be able to pay for the other half it would be a better option and I would not have to spend hours and sometimes you have customers to serve so time is a problem.

Edd, in interview transcript 4, also prefers to buy his own medications, saying '*I thought it was better for me to buy my own drugs*'. He also complains about the social disruption caused by the time spent in the queues because according to him '*the queues for example were long and there was such and such that would be required and also this habit of being referred from one place to another as if they do not know who is supposed to be doing what*.' It also brings a sense of frustration of having health personnel who are themselves unsure of what they are meant to do. All this seemed to add to the '*confusion*'. Wasti et al (2012) in a study undertaken in Nepal, arrived at a similar conclusion. Of importance to this study is the identification of not only transport costs and side effects but pill run-outs and patients who profess being busy are cited as reasons contributing to out of pocket payments. Interview transcript 9 below describes the frustration at the time spent in the many queues, as Jim and Andrew narrate below:

Interview transcript 9 “You come back again and join another queue.”

Researcher Did you experience queues?

Jim I have spent time in queues, sometimes you go there around 6am before they open and you can come back home around 2 or 3 pm.

After you have paid the dollar, they stamp your card, and then you come back again and join another queue for those receiving their pills. But before that, you have to join another queue for the scale after they finish checking your weight you then collect the ARV's from a small window.

³³ One of the main public hospitals in Harare.

The workers start work on time they start at 8 o'clock but because they want to conduct a church service. You expect them to have the church service on a Sunday. When this is over people queue and can now be served. After this the pills go out of stock. They wouldn't have told you they did not have enough pills. After you leave the clinic it will be around two o'clock and you sometimes would not be having the pills. So what do you do? Your whole day is wasted. It is better to buy on your own and you know you can get your pills when you need them without these formalities and having to wait endlessly in the queue.

Interview transcript 10 “There are a limited number of people that that can be attended too...”

Researcher Why are you unable to be there on time?

Andrew No, the kombis do not start operating very early in the morning. Sometimes because I have people who need to have their cars sorted, I have to finish repairing them and by the time I finish it would be late so the hospital will be closed. So it means I have to put up near the hospital so that I can be attended to early and I can rush and fix my customers cars. The other thing is because the ARVs are free the queue will be long and you will not be the only one wanting to have a CD4 count and viral load done. There a limited number of people that can be attended to, so if you are late you will have to come early the next day to book your sport. Work will not stop because you have some CD4 count to be done.

5.3.3.2 Stock outs

According to the National AIDS Council Annual Report (2012:31), stock-out occurred during 2012, with Tenofovir, Zidolam-N, Coviro, Stalanev, Tenolam, Lepinavir and Triomune-baby all running out. The unavailability of stock in the public health facilities was another factor that influenced the decision to opt to pay for treatment as Jim; interview transcript 9 and Edd in interview transcript 3 below highlight. Jim says ‘the issue was that, sometimes we encountered challenges of not having the actual stock and the queues that happened to be there’. While Jim contends ‘Every other month or two months there is a stock out’ Vian et al (2005:18) note that in Albania out of pocket payments were spurred by the perceived quality of service “fear of being denied treatment”. Productive time is lost waiting in a queue only to be told later that the drugs are out of stock. In transcript 4, avoiding medications which will run out affects the decision to pay out of pocket. The notion of medication running out after spending half a day in the queue is a strong motivator for paying out of pocket.

Interview transcript 4 “You might as well buy them yourself.”

Researcher Did you try to enrol for treatment here in Harare?

Edd I tried; the issue was that sometimes, health facilities did not have the actual stock and the queues that happened to be there. You could go, there was a time people would spend a week there and not be served. They would have spent a whole week there without being served. They would go and spend the day and not be served and come back the following day and spend the day without being served and this could go on for a week with you not having been served. When your chance comes for you to be served you are then told the pills are no longer there. You might as well go out there and buy them yourself, since the stock is sometimes there and sometimes it is not.

Interview transcript 8 “I wouldn’t want to go to a public facility I would want to do my own private thing.”

Researcher What were your reasons for opting to buy the ARVs on your own?

Shungu Well for starters, I read the papers your find that the drugs you are referred to in the public facilities sometimes they go out of stock and there are long queues which is what I wanted to avoid.

Kagee et al (2007) point out that the high unemployment attaining in many low income countries makes a visit to the public health clinic a disincentive. This is the case where it might interfere with the prospect of an income or place the patient in a position where he/she is susceptible to lose their job as Precious in interview transcript 16 laments.

Interview transcript 16 “You cannot keep on asking time off your employer.”

Researcher Why do you pay for ARVs?

Precious The reason I pay for the ARVS is because usually they give us a supply for three months. But when that supply is finished, and you go to the clinic to get another supply sometimes they tell you they do not have your DN pills³⁴ in stock so you can come back two or more times without the pills in stock. So you cannot keep on asking time off your employer to go and check if the pills are now in stock. That is why I decide to buy the pills on my own.

The non-availability of other treatment drug options or the prescribed ones in the public health facilities was a factor that informed PLWH to elect to buy ARVs. Ropa in interview transcript 2 below brings this out when she says *‘I have a sister who works at an OI clinic in Kadoma, had the*

³⁴ Douvir-N is an antiretroviral medicine taken twice daily.

drug been available at the hospital there I would have definitely gone to the hospital, because it was very expensive for me'

Researcher Your choice of treatment facilities, what influenced it?

Ropa I have a sister who works at an OI clinic in Kadoma, had the drug been available at the hospital there I would have definitely gone to the hospital, because it was very expensive for me. When I was finding a cheaper way of obtaining this drug and I even made inquiries to some people on diplomatic missions in Singapore who said if I sent money they could buy it for me. I just let it go and said ah let me see how it goes.

Researcher Was Truvada and Efavirenz available in public health facilities?

Ropa Efavirenz was available in public hospitals; Truvada was still a fairly new drug on the market.

Researcher Before First Mutual Life stepped in who paid for the ARV's?

Ropa I had to pay, the whole amount to purchase that from the Pharmacy, because this Atripla is not available at health institutions and I tried. I went around the centre everywhere I could think of, where I could get the drug cheaper. They didn't have it, which was rather sad. It has worked real wonders for me I never suffered any side effects.

In the case of Admire in interview transcript 14 below, systemic issues that can be located in the inability of the first health provider to render the required service (diagnostics) due to capacity issues and lack of electricity, contributed to coerce him to seek diagnostic help at a subsequent health provider at a higher cost from a private health service provider.

Interview transcript 14 "The clinic I go to does not have the machines to do these tests."

Admire Yes, I pay to have my viral load and my CD4 done when the time for them is due.

Researcher Why do you pay?

Admire The clinic I go to does not have the machines to do these tests. So they referred us to another clinic but sometimes you go there they tell you they do not have the chemicals to be able to do the CD4 or viral load. In some case they will tell you they cannot operate the machines as there is no ZESA³⁵ and they cannot tell when ZESA will be back so you can spend the whole week going there and find the machines not operating. You would have run out of pills and if you skip the nurse at the clinic where I collect my ARVS will shout at you and warn you that the next time you skip taking the pills you should not come there again as you are a nuisance. So the best is to go to a private laboratory and get these done.

Researcher Do the alternative clinics not have a generator?

³⁵ Zimbabwe Electricity Supply Authority, a state power utility normally used in slang to represent electricity.

- Admire Some do but most of the time they do not have diesel as they use the generators for other things as well. Some clinics just do not have them or they would have broken down.
- Researcher How much does it cost to have your laboratory tests done?
- Admire For viral load I pay 50 dollars and for the CD4 count I pay 30 dollars.
- Researcher How often do you need to have these tests done?
- Admire Every six month.

5.3.3.3 Perceived of quality of service

Sometimes the perception that respondents had of the health services in terms of attitude of health staff towards patients and the nature of the prophylaxis available influenced their treatment seeking behaviour. In transcript 8 below; Shungu notes drugs that may have expired. It is these events that she witnesses that reconfirm or reinforce the quality of service and commodities as reported in the papers and she then asserts that *'When you see things like that that's when you say to yourself OK if it's now in my position what would I opt for, hence my decision to buy my own drugs'*. The issue of expired drugs being dispensed also concerns Shungu, and she points out that *'So I personally believe in having drugs that have a valid date...'*. The quality of medication is seen as a factor in lack of adherence, according to a study undertaken in Malawi by Hosseinipour et al (2006).

Interview transcript 8 "No even if it's expired they have a shelf life of three months."

- Researcher Is that what put you off? The reports from the papers?
- Shungu I witnessed while escorting them to the hospital that the drugs they had been given had expired for that month and I also witnessed that there were long queues in getting these same drugs. What the nurses said when I asked them was 'no even if it's expired they have a shelf life of three months'. So I personally believe in having drugs that have a valid date so to speak instead of having drugs that are expired and long queues and the time they get to collect them. So it's something I witnessed. When you see things like that that's when you say to yourself OK if it's now in my position what would I opt for, hence my decision to buy my own drugs.

In interview transcript 6 below, Passmore would rather travel to Bindura which is 88 kilometres from Harare to seek treatment as the services there were fast, free and the staff are friendly. In the case of Ida interview transcript 18 below, it is the personal attention received from the doctor and the chance to be checked for other unrelated health conditions. The quality of care literature in chapter two, specifically, Jain (1989) noted the issue of how patients are treated by health service providers as important. The availability of medicines and functional equipment as pointed out by Collier (2003), Dercon and MacKinnon (2003); Lavy and Germain (1994) make Passmore in the above caption satisfied with the level of service he gets to warrant this trip to this public hospital out of town. It is

also only Passmore and Ida as patients who are better placed to determine whether the health services are of the desired quality as Morgan and Murgatroyd (1994) have pointed out.

Interview transcript 6 “The service is good.”

- Researcher Have you ever thought of changing collecting your ARVS from Bindura to Harare?
- Passmore Why should I? I can easily go to Bindura even if I have no jobs there. The service is good, the moment you get there they serve you there and there, there is not a time you can really say you spent waiting for ARVs. The staff are very friendly and kind. The moment you get there they give you what you want. Unless they change the procedure you never know, as drugs can get better and if they are better drugs in Harare I will change.
- Researcher Are ARVs free?
- Passmore Yes it's free?
- Researcher Are laboratory tests free?
- Passmore Yes, but I have not seen any doctors yet.

Interview transcript 18 “The doctor has time to listen.”

- Researcher Why don't you transfer from private to a public facility?
- Ida Using my Doctor makes sure I get the personal attention as there will be no long queues that he has to deal with. I also get the right medication that corresponds to me and I am closely monitored by my doctor. During my visits, I can get other tests done besides checking my weight as they do in public health facilities. Usually after my CD4 count test results come out, the doctor explains them to me and what I need to do to improve on my CD4 Count and the Doctor answers questions without being angry. Like the other time I had an ear infection, which he was able to attend to and yet I had gone to get my CD4 count results.

5.3.3.4. Absence of health insurance³⁶

The absence of health insurance resulted in paying out of pocket expenses. This is a challenge and implies making the choice to forgo other necessities, as interview transcript 3 reveals. It also shows the cushioning effect of health insurance. According to the Zimbabwe Health Assessment Report (2010:16), less than 1% of the population in Zimbabwe had health insurance. As Ropa in interview transcript 3 relates *‘but now the figure for Atripla is sixty dollars and this is a bit steep, because CIMAS my health insurance company was not willing to pay for the drugs’*. In the same narrative a sense of relief from having to look for money and buy drugs comes out where Ropa says *‘so [First*

³⁶ The researcher found out that one of the largest health insurers (Public Medical Aid Society) was not being accepted in most private hospitals and pharmacies (random interview with 17 private pharmacies in HMP).

Mutual Life] gave me a sense of relief because it covers my ARVS so I do not have to look for money to buy Atripla'

Interview transcript 3 “I was relieved.”

Researcher Before First Mutual Life stepped in who paid for the ARV's?

Ropa I had to pay, the whole amount to purchase that from the Pharmacy, because this Atripla is not available at health institutions and I tried I went around the centre everywhere I could think of where I could get the drug cheaper.

However, most of the PLWH interviewed lacked any form of health insurance, where it was provided by the state it was insufficient to cover the costs beyond user fees in public health institutions as in the case of Chamu in interview transcript 1 and Gogo in Interview transcript No. 2 chronicle. Laboratory tests are a prerequisite to access free ART. The laboratory tests as well as the need to obtain proper diagnosis and treatment, have financial ramifications, especially where health insurance is not available to cover the costs of diagnosis and treatment. The interview extract below shows how access to ART can appear to be easy yet it is actually very difficult unless a person has the resources to pay out of pocket. In questionnaire 31, the respondent tells how ART caused a burning sensation in the legs, which caused the respondent to switch to another type of ART. This was not stocked in the public health facilities, as it was not commonly used. This necessitated the need to pay out of pocket for that particular ART. The fact that health insurance is acceptable to all health service providers both in the public and private domain is not beneficial especially for those in the informal sector or the unemployed. This is further amplified in the interview extracts, where a letter from social welfare (AMPTO) was not helpful for example in Interview transcript 2 (Gogo) and 1 (Chamu).

Interview transcript 2 “This letter is not accepted.”

Gogo They encourage us to have our CD4 tests. They want to see what the CD4 will be like before they give you the pills (ARVs). I have two month's supply of pills (ARVs) left. I need to look for money soon to have the CD4 done so that I can be able to get my pills before they run out. Before, I used to find money through selling, but due to the pain in my legs I am failing to do this. I do not know the cause of this pain in my legs, perhaps the pills may have something to do with it. This is preventing me from doing the necessary work that I need to do to earn money such as going to commercial farms and rural areas to sell various things I would have ordered

Researcher What is holding you back in terms of finding the required money?

Gogo I do not have money.

Researcher Don't you have medical insurance?

Gogo No, I tried to use the AMPTO³⁷ but ...This letter is not accepted by the hospitals and the doctors that I would like to see for the diagnostic tests for my CD4 and legs. So you feel you have no power in all these things.

Chamu in interview transcript also notes the inability of the social welfare based assisted medical payment order to help.

Interview transcript 1 “I am asked to bring to the hospital my own dressing...”

Researcher Do you have medical AID?

Chamu No, I have approached this organisation to tell them that the letter they gave me to take to the Ministry of Labour and Social Services only resulted in me getting this AMPTO. The problem with this AMPTO is you cannot use it in private clinics and pharmacies to get the doctors to have a thorough look at your condition. They all have been asking for cash up front. When I went to the public general hospital they gave me a list of things that I should bring such as my own dressing, betadine, latex gloves, cotton wool and G.V. paint. They told me AMPTO does not pay for these but I could be assisted without paying the 5 dollars for the card.

5.3.4 Coping mechanisms

This section illuminates the coping strategies caused by direct cost to treatment and as a result of treatment seeking behaviour based on the categories suggested by Flores et al (2008), Russell (2004), McIntyre et al (2006) among others as providing a mechanism for households to respond to health shocks.

5.3.4.1 Reason for borrowing

Trust, in transcript 5 (below), states that unpredictability of income curtails his borrowing ability: *‘and you cannot borrow every time as you have no plan of how you will pay back as you do not know if next day or two you will have customers’*.

Interview transcript 5: “you cannot borrow every time.”

Researcher How often have you borrowed and why?

Trust I have borrowed many times. This was because sometimes when I run out of pills, I will not be having money. So I try borrowing from different people who can help like my brother and some of my friends. But you cannot borrow every time as you have no plan of how you will pay back as you do not know if next day or two you will have customers.’

³⁷ Assisted Medical Payment Order is a letter from the Ministry of Public Service and Social Welfare normally issued to those that cannot afford.

Borrowing by Andrew in interview transcript 10 below is out of necessity as it is difficult to set aside or save money for the time when it is necessary to have a CD4 count test done. Borrowing creates a vicious cycle due to the need to pay for other domestic demands.

Interview transcript 10 “So you end up borrowing.”

- Researcher Does the cost towards your health affect the way you live?
- Andrew Yes, since sometimes it is difficult to find the money for the CD4 count and viral load as you cannot budget money which you do not know when it is going to come and also there are other things like rent, food, clothes, electricity and relatives who look up to you for support. So you end up borrowing and this means you have to pay the people who would have lent you from the little you get.

5.3.4.2 Reason for selling an asset

This code describes the reason why an asset was sold and type of asset had to be sold in order to seek treatment or diagnostic services. Selling of assets to pay for treatment related costs is evident from the narratives below. Gogo in interview transcript 2 talks of selling her prized bull, Chamu in interview transcript 1 and Almustafa in interview transcript 15 who sold a cell-phone, while in the case of Sasha in interview transcript 11 and Tendayi in interview transcript 12 it involved the sale of productive assets (sewing machine and cart). Gogo sold both productive and consumptive assets in the form of livestock as narrated in interview transcript 2. These assets were sold to pay for treatment and diagnostic tests from a subsequent provider a private pharmacy since they were out of stock at the first provider, a public hospital. Sauerborn et al (1996) note that the sale of assets is common to meet health costs.

Interview transcript 2 “I sold my cattle.”

- Researcher Describe the livestock that you sold?
- Gogo I went to N’angas some of whom demanded my livestock until I had none left... I sold my cattle and had to offer the traditional healer chicken and goats as part of the sacrifices that had to be made towards my ancestors. The sale of the cattle, one of which was a bull was partly to pay the traditional healers for their services.

In the case of Gogo in interview transcript 2 above, the form of livestock that had to be offered in kind or sold is vividly described. These livestock are either productive or domestic/consumptive, productive in the case of the bull that can be used for ploughing.

Interview transcript 15 “To pay for my ARVs.”

- Researcher Why?

Almustafa I sold the smart phone my mother had bought me as a present for 35 dollars. This phone was bought by mother before her death to pay for my ARVs. I was told they were out of stock at the hospital where I normally collect them, so I had to buy them from a pharmacy in town.

In the transcript 11 below; Sasha sold her sewing machine which was a productive asset that was used to add value to the goods that she sold to pay for medication and for food.

Interview transcript 11 “I sold the sewing machine.”

Researcher Have you sold any household asset to meet your expenses?

Sasha Yes I was forced to sell my sewing machine. I also sold the sewing machine so that we could have some money for my medication and food to survive on. I sometimes used the sewing machine to mend some of the second hand clothes that I sell.

In interview transcript 12 below, Tendayi’s failure to find someone to lend him money forced him to sell his cart which is also his means of livelihood to pay for diagnostic tests that were a conduit to having access to ARVs besides his clothes.

Interview transcript 12 “I sold my push cart after I failed to find someone to lend me some money”.

Researcher Have you ever sold an asset to pay for your health costs?

Tendayi I sold my push cart that I use to ferry customer’s goods after I failed to find someone to lend me some money to go and access tests for my CD4 count, viral load test and to collect my ARVs... The sale of the push cart has affected the way I am able to make a living as I cannot earn money to sustain myself and to buy another one.

Researcher What else have you sold to access treatment?

Tendayi I sold some of my clothes to find money for transport to collect my ARVs and to also buy food. You cannot take these ARVs on an empty stomach you need to eat.

In the case of Admire in interview transcript 14 below, the reason an asset was sold was to be able to pay for diagnostic tests such as the CD4 Count and Viral load.

Interview transcript 14 “I sold our wardrobe.”

Admire It was to pay for the laboratory tests to have my CD4 count taken and to have them check my viral load. I sold our wardrobe to a colleague so at the moment we just pile our clothes on those boxes there. Perhaps one of these days I will be lucky and will get enough money to buy another one.

In the case of Almustafa, the selling of a cell phone was more than just a socio-communication tool but a productive asset as its use is explained in the creation of value. The cell phone is a productive

asset in the sense that it is used to communicate with potential clients and it assists in getting his work done. That the smart phone was sold and not replaced has to do with poverty.

Interview transcript 15 “It was my personal computer.”

Researcher Have you sold an asset to pay for your treatments?

Almustafa I sold the smart phone my mother had bought me as a present for 35 dollars. This phone was bought by mother before her death.

Researcher Did the sale of the cell phone affect you?

Almustafa It did, this phone was very useful to me as it made it possible to communicate with customers and others using whatsapp which is very cheap instead of texting. I could also go and take pictures of jobs that my boss would have received an enquiry to repair. It enabled me to use it for many things, it was my personal computer. So it also had a radio, and many applications that I do not have on this phone that my boss donated to me. It only enables me to receive and make calls only.

5.3.5 Effects on physiological needs

Arrow (1963:1941) contends that, “*at low income levels, effects on other commodities such as nutrition, shelter, clothing and sanitation may be more significant*”. While the impact of hardship financing of health can be mitigated by coping strategies as shown above, it resulted in food and clothing insecurity that negatively affects the household budget in general as will be explained below. Income is not the only variable by which to assess the levels of poverty caused by treatment seeking behaviour and the direct costs for paying for it. It can also be in the form of calories consumed per day that are necessary for social and economic reproduction as Rodney (1982) observed. In the interview transcript 14 with Admire and Ropa in Interview transcript 3 the meals are basic and repetitive lacking additional nutrition which are a source of nutrients essential for PLWH. In a study in Vietnam, Nguyen (2012) showed the likelihood of reduced food consumption due to the high costs of treatment. In addition to food and clothing, there are other competing priorities beyond just the physiological that households have to contend with as explained by Precious in interview 16.

Interview transcript 14 “We have two meals twice a day.”

Researcher How have you been able to cope with the laboratory tests in terms of your household budget?

Admire I know that every three months I have to go to have my CD4 and viral load checked that is what the nurse told me at the clinic to do before I can get my supply of ARVs? I put aside some money every month towards this expense. So it means that

It affects the way we live. We have two meals twice a day, normally sadza³⁸ and dried vegetables or matemba³⁹, but sometimes my employer provides lunch so I will be able to have three meals a day and some meat. But life is very difficult as trying to make ends meet is tough. I thought of going to South Africa to work, but the time I had the opportunity to do so, I was very sick and my wife had to look after me so I missed the chance. Now it is very hard to go there as they demand that you have a work permit.

The interview above also highlights the plight of making ends meet for ordinary Zimbabweans who see better hope in migrating to neighbouring countries such as South Africa where there is, relatively, a greater likelihood to get formal employment..

Interview transcript 3 “It was a hand to mouth situation I was faced with.”

Researcher How did paying for treatment make you feel?

Ropa You know? It was a question of life and death, I had to forgo so many things because as you are aware our salaries are not that much and sixty dollars and an additional two dollars for Cotrimoxazole is rather too much for me. I have two children who need attention; one is in University and needs money every month. You know? It really affected me so badly; I also needed to eat healthy food although it was a hand to mouth situation.

The inability to replace consumer goods such as wardrobe and television often sold to meet health costs and dependency on second hand clothes is another indication of poverty. As Admire’s family in interview transcript 14 below, explains how paying for diagnostic tests led to this situation. In addition, the inability to replace the broken down television, which has denied the family with some form of information and education comes out in the interview. Debt is a problem too, as the household is intractably in debt according to the interview.

Interview transcript 14 “We have not been able to replace the sofas.”

Admire It was to pay for the laboratory tests to have my CD4 count taken and to have them check my viral load.

Researcher What did you sell?

Admire I sold the wardrobe and could not get my television fixed.

Researcher How did that affect you?

Admire We do not have anywhere to put our clothes. Besides piling them up on top of those boxes as I have not been able to replace the wardrobe. Besides, we hardly

³⁸ Thick porridge which is a staple in Eastern and Southern Africa made of maize meal or other types of grain or cassava.

³⁹ Dried sardines.

have any furniture. We do not have a television or radio to entertain us. We do not have even basic things like toys to occupy my children. So sometimes, my children go to the watch cartoons from the other tenants or from their friends in the neighbourhood. My own television has broken down and it has been repaired several times now, the parts required are as good as buying another good second hand television. Business has not been very good so replacing the wardrobe or buying another second hand television is at the moment not a priority as there are other needs like paying the debt for food and clothing for the children in my case as you can see; this work suit is also what I wear even if I am not working.

In interview 11 with Sasha below, what comes out is the failure of society to afford new or second hand clothes. These are usually sourced from charities in Europe and the United States and sold in flea markets, instead, people opting for cheaper and inferior quality clothes from China (*Zhing Zhongs*). At personal level, it is the inability to be able to replace the productive asset she sold.

Interview transcript 11”People prefer to buy Zhing Zhongs.”⁴⁰

Researcher How did that make you feel?

Sasha It made me very sad as it is difficult to replace these items, especially my sewing machine. Selling second hand clothes is no longer profitable as before, since people prefer to buy Zhing Zhongs as they are cheaper. Sometimes you can go for weeks without finding a client in the nightclubs but no one will say do not pay for this because you failed to get customers. They all want their money the shops, land lord and all others.

5.3.6 Impact on household income

The catastrophic effects of paying for treatment on the household budget are clearly articulated in the transcript interviews 5, 4 and 10. Here treatment costs are one among other competing domestic demands that result in families forgoing other necessities. The catastrophic nature of out of pocket payments has been defined differently according to Pradhan and Prescott (2002); Wagstaff and van Doorslaer (2003); Russell (2004); van Doorslaer et al. (2007). They describe it as being a portion or percentage of household expenditure spent on out of pocket payments on HIV care that exceeds 10%. Hortsberg (2003) and Trujillo (2003) argue for a portion of the household expenditure directed towards health costs as a better proxy for ascertaining of health care costs. Interview transcripts 5, 4 and 10 highlight a significant portion of household finance that goes towards treatment costs.

⁴⁰ Slang for Chinese goods which are of inferior quality but normally sold very cheaply.

Interview transcript 5 “The proportion spent on drugs is a lot.”

- Researcher How does buying treatment affect your domestic budget?
- Trust It does affect my household budget as I am the only one able to do this and that (Kiya Kiya), my wife is also unemployed but cannot find anything yet to do to also kiya kiya and we have a very young family so my wife has to stay at home and take care of it. So if you look at it, it is a chunk of my budget as I have to pay rent, food and so forth every month so it's a big problem. The proportion of money spent on drugs is a lot, if you count this as food cost money, plus the drugs. Per month, I use about three hundred and seventy dollars, it will be for everything including the fifty dollars for the drugs
- Researcher Is it easy to find fifty dollars a month for Tenolum E?
- Trust Eish! it is very difficult. It is very tight! That's why I have to do this and that (Kiya Kiya) so that at the end of it all, I can be able to put together some money to at least be able to pay for half of my medication that is twenty five dollars and then part of the remainder when I have found the money.

In the interview transcript 5, above, what comes out clearly is the struggle to make ends meet so that money can be found to pay for part of the treatment. The proportion of money spent monthly on treatment in relation to the overall monthly budget is significant. Spending on HIV treatment *ceteris paribus* will increase patients' costs, resulting in deterioration of a household's customary standard of living, as argued by O'Donnell et al (2005) (2007), Xu et al. (2003), Gerfter and Gruber (2002).

Interview transcript no.4 “So a significant amount of my income is directed towards my treatment.”

- Researcher On average how much did you spend on household expenses including your medication?
- Edd I think about one hundred and fifty dollars, and the fifty dollars part will be for the medication. So a significant amount of my income is directed towards my treatment.

In the interview extract above, according Edd a third of his monthly expenditure goes towards treatment costs, this type of monthly health expenditure has a catastrophic effect on the monthly household budget. Barros and Bertoldi (2008) showed that in Porto Alegre, Brazil, household expenditure for medicines accounted for 47% of household expenditure. A large fraction of household resources was spent on health care payments, and this caused impoverishment. This is further illustrated and supported in studies by Xu et al (2003), Gertler and Grubler (2002). In the case of Andrew in interview transcript 10 below the amount that has to be budgeted for is more than USD40 every six months for diagnostic tests such as CD4 count and for transport including that of his wife.

Interview transcript 10 “But then I will also need some money for food.”

- Researcher Does your wife work?
- Andrew No she used to do cross-border trading. But now as you can see it is difficult to buy things and sell from South Africa as there are many things now available from South Africa and the Chinese people, so she sits at home and looks after the children. Although she is a qualified secretary the company she worked for closed down.
- Researcher Your average month expenditure?
- Andrew We work with bout USD240. This has to cover rentals for the place I operate from. The house I am staying in is mine. I also have to buy food and other expenses at home, pay for the crèche where there is one of my children besides the burden of laboratory tests which costs more than USD40.
- Researcher Why do you need to have more than USD40 every six months?
- Andrew This is because the hospital charges me USD20 to have the CD4 Count test done and the other will be USD20, for my wife to be checked too so we will need another USD40. The kombi’s for both of us will be USD2... It’s not as easy as saying you budget for these things, it’s a struggle I do not know how we can be able to make ends meet. It’s very hard to be with HIV as it is expensive.
- Researcher How much do you earn per month? On average that is?
- Andrew My average income is about USD240 a month as there is a lot of competition from other mechanics.

In the case of Precious the direct cost of treatment is more than half her salary, she narrates how this has affected her long term career prospects.

Interview transcript 16 “I wanted to go for agricultural or nursing training.”

- Precious They cost 40 dollars for a month’s supply.
- Researcher What is your monthly income?
- Precious I am paid 70 dollars a month.
- Researcher Pertaining to the amounts you pay for treatment: How do they affect your livelihood?
- Precious The amount I pay affects me in several ways. I have to budget for the treatment in case they tell me they do not have the pills. But I have other expenses for food, clothes and the need to support my three brothers, one in grade three, the others in forms two and three with school fees and sometimes uniforms. So there is hardly any saving I can make so I am in debt towards either my employer or friends. With my employer, instead of paying back, I work extra hours to cover for the money.

- For my friends I pay them bit by bit.
- Researcher Would you have liked to further your studies?
- Precious I passed my Ordinary-levels and would have wanted to go for agricultural or nursing training and then continue with my studies to university until I am 27 or 28 years. I am 21 years. I would like to continue with education but I have to work to get money for my medication. My brothers are in the rural areas with my parents, who do not have much so I have to support them by sending my brothers to school.

5.3.7 When resilience fails: the consequences of direct cost of treatment and diagnostics

The cumulative effects of direct costs associated with treatment seeking behaviour and or the inadequacy of coping strategies as discussed above can break the resilience of the households. This forces them to adopt other measures beyond coping strategies in order to mitigate the debilitating effects of poverty through; seeking services of traditional healers, transactional sex work, staying with multiple untreated infections, work for treatment by young people, proliferation of self-treatment, periodic defaulting on drug and diagnostic treatments. It is in this context that this section intends to shed more light on why these factors arise, normally signalling failure to adequately meet the direct costs of treatment.

The issue of limited income possibilities permeates the interview with Edd below in interview transcript 4, Ida in interview transcript 11, Chamu in Interview transcript 1 and Sasha in Interview transcript 1 below. In these narratives, it is important to note how people are forced to choose cheaper alternative treatments. This type of decision-making conforms to the *law of demand* as Frey (1992) and Frank (1994) observe. Kahneman and Tversky (2000) have argued that individuals put more emphasis on financial losses than on health gains.

It is also worth noting that Edd's decision to use a traditional healer, Sasha's option for transactional sex and over the counter purchases, Precious defaults while Chamu opts to self-treat; this has to do with the price inelasticity of ART being paid out of pocket from a private pharmacy. Here, studies by Goodie et al (2007), Varian (2006), Field et al (2006) and Summall et al (2004) are informative in understanding this type of behaviour. According to Goodie et al (2007) price and quality influenced decisions to pay for controlled drugs.

5.3.7.1 Use of traditional medicine

Although traditional medicine was seen as an alternative in so far as it was less expensive, Falkingham (2004:250) notes that cost of health can affect health seeking behaviour. Patients resort to the use of unproven treatment which might end up being sub-optimal and for this respondent with critical skills, it implies their inability to apply their productive labour to good use, as the narratives below illustrate.

Interview transcript 4 “I started taking the traditional medicine.”

- Researcher What made you opt to use traditional medicines instead of continuing on ART?
- Edd I had economic challenges. I was not getting customers who wanted to have their IT⁴¹ things fixed so money was very difficult to find and you cannot borrow every time as you have no plan of how you will pay back as you do not know if the next day or two you will have customers who will be able to give you something. I got advice from other people who had been on ARV's and had gone to the traditional healers, and were helped.
- Researcher Can you elaborate on the economic challenges that made you take this choice?
- Edd Since this work of ours is not stable you can spend some time without any work coming your way. Money then will not be available every month to enable you to buy medication. It was challenging after five months, the problems begun to arise as I could not find some work to do in order to get money to pay for the medication. So when I got ill the second time, someone advised me of a certain traditional healer who was helping other people. I decided to visit the traditional healer. I was happy I did not have to spend money every month taking tablets every day which would not make me cured.

The interview transcript above reveals that economic factors associated with the cost of drugs can influence decisions to seek alternatives. In the case of the above narrative by Edd especially at the end, despite the cost ARVs, they cannot cure HIV. Edd seems to be convinced about the opportunity cost of a life-long treatment that can be achieved conveniently in a month through herbal uptake. Edd notes that, taking ARVs was not a *fait accompli* treatment for HIV ‘*ARV's were useful but the problem is they can't eliminate the virus?*’ Hammond-Tooke (1989:85) argues that while it might be therapeutic for the victim to ascribe the source of HIV to witchcraft, it often comes at a high price for the victim who dies

5.3.7.2 Transactional sex work

The multiple issues in interview transcript 11 below with Sasha highlights three interconnected things, namely; the need to engage in sex work so as to get supplementary cash to pay for her ARVs and antibiotics, the lack of social and health insurance to assist in the payment of fees for her two children and the need for transport for her to have CD4 count done at a site outside Harare managed by an NGO. Poverty increases the susceptibility of households of contracting HIV among other infectious diseases which further weaken the ability of households to reproduce themselves. That is, poverty predicates sexual exploitation and gender inequality as the interview transcript 11 below shows.

⁴¹ Information technology

Interview transcript 11 “That is why I am forced to go out to nightclubs”.

- Sasha That is why perhaps I am forced to go out to nightclubs at night to look for clients who can pay me extra money to be able to meet my treatment costs besides those expenses such as costs for my tablets and school uniforms for my son. As on my own, I fail to meet them. Even if I borrow, the amount is very little and I have to pay it back. Remember I have children to look after and my medication which costs a lot and to get my stock of second hand clothes bales — all have to be paid in cash. I also have to pay kombis to go into town to the night clubs to look for money and in all these things you cannot negotiate.
- Researcher How often do you go out looking for clients in night clubs?
- Sasha Normally on Fridays or weekends as I will not have any one to leave the children with. Sometimes, I do this during the week if things are very tight or usually during the end of the month. This is when I can even go and sleep out with a client if they are willing to pay more.
- Researcher How much do you pay for your prescription a month?
- Sasha My drug costs USD57 that is for the Atripla.
- Researcher Are there any other medicines you buy?
- Sasha Yes, I pay USD2 for Cotrimoxazole as I normally have bouts of pneumonia and pay for a 7 day course for erythromycin to treat some of the infections that I would have developed.
- Researcher Have you had any CD4 done?
- Sasha Yes
- Researcher Did you pay for them?
- Sasha No
- Researcher Why?
- Sasha Because I go to the MSF Clinic in Murambinda to get it checked as it is free there. But I need to have dollars on me for transport and food. Since I will spend the day travelling to and from Murambinda I need to buy something to eat as well.

5.3.7.3 Coping with untreated multiple infections

The issue of having HIV compounded by another chronic illness and wounds unattended too is highlighted in interview transcript 1 below with Chamu. The narrative explains how direct costs of treatment can affect adherence to treatment, the lack of money to pay out of pocket for the ARVs when they are out of stock from first provider as they normally are, and the financial burden created by the need to have a CD4 done, diabetes and wounds attended to.

Interview transcript 1 “I am asked to bring to the hospital my own dressing...”.

Chamu I have paid for ARVs and it seems I am now doing this every month. This is because the queues are long and they may not have the pills in stock since I take TenoLumE⁴². These are the latest ones I am told as I take one pill a day. This was after the doctor suggested that I should stop taking the pills called Stalanev as I was reacting to them and after I told the doctor I would prefer not to take them.

I am also diabetic and this has caused severe sores on my foot, to have these attended to I will have to join another queue. Normally, because of the nature of my sores I am asked to bring to the hospital my own dressing, betadine, cotton wool, GV paint and latex gloves so that my wounds can be attended to. So I have to buy these from the pharmacy where I buy my ARVs.

5.3.7.4 Periodic defaulting on treatment and diagnostic test

Patient treatment was interrupted by cost, as noted in studies undertaken by Wasti et al (2012), Johansson et al (1999), Khan et al (2000), Greene (2004) and Watkins et al (2004). Lack of money to buy ARVs resulted in many of the respondents defaulting on taking their medication. This makes the HIV virus resistant to treatment and results in further complications which cannot be adequately addressed by the weak health system as noted by Reynolds et al (2003), El-Khartib et al (2011) and Wang et al (2011) among others. As the two cases Edd in interview transcript 4 and Precious in interview transcript 16 below explain what happens when they do not have the required money to buy antiretroviral medicine. In the case of Edd it's “skipping taking the pills” as he elaborates;

Interview transcript 4 “I would skip taking the pills for a month.”

Researcher Can you elaborate on the economic challenges that made you take this choice?

Edd Since this work of ours is not stable you can spend some time without any work coming your way so money then will not be available every month to enable you to buy medication. It was challenging after five months, the problems begun to arise as I could not find some work to do in order to get money to pay for the medication. Because of this challenge, I would skip taking my tablets for the month. I would not be having the cash to buy the required medication for the month at that point, which is USD50. If I run out of tablets, before I have money I would have to wait taking the tablets until I had money to pay for them.

⁴² Tenofovir/ Lamivudine and Efavirenz are antiretroviral medicines.

For Precious, the consequences are “staying without” as she explains;

Interview transcript 16 “So I stay without.”

Researcher Have you failed to take a pill and what was the reason?

Precious These pills are free but when they are not available at the hospital I am forced to buy them from the private pharmacy. But sometimes I will not have the money to buy them and the people I normally borrow. If I fail to have any I just stay without?

Researcher Normally for how long have you stayed without the pills?

Precious Two days. When I resume taking the medication my chest will be painful. But there is nothing I can do if I can get Panadol to ease the pain...

Trust would rather wait until he is very sick before he can be able to undertake diagnostic tests to assess whether the HIV virus is being sufficiently suppressed as he says:

Interview transcript 5 “So I would have to wait until I am very sick.”

Researcher Have you gone for laboratory tests?

Trust No, again it’s a question of money. The doctor charges you consultation fees about USD22 dollars to write you a referral letter. You take this to the laboratory near the surgery and then there you can get your CD4 count done for forty dollars. If I added that to the money that I would have to find for the drugs too it is too much. I am not able to make ends meet. So I would have to wait until I am very sick perhaps that’s when I might go for a CD4 count, to check and see at what level my CD4 was and other tests to determine if the virus was still active in my body. It’s the price and the lack of a source of money that would be able to support this expenditure without starving my family or getting into debt that would be difficult to pay from my *Kiya kiya* jobs.

5.3.7.5 Proliferation of self-treatment

In interview transcript 11 with Sasha and Interview transcript 6 with Passmore, self-treatment was used to avoid paying for user or consultation charges. As has been noted by Gotsadze et al (2005), in a study in Georgia, patients resorted to self-treat due to lack of money to pay for doctor consultations. These actions underlie the lack of financial means to pay for appropriate physician consultation that might typify poverty.

Interview transcript 11 “I just ask the pharmacist to sale me the tablets”.

Researcher How do you obtain these antibiotics? Do you have to consult a doctor?

Sasha No, Doctors are another expense they charge you USD20 to 25 dollars depending on which doctor you would have gone to. You find out that the actual prescription will

normally be less than 10 dollars. So I just ask the pharmacist to sell the tablets⁴³ to me, after I describe the nature of sickness. After all, the pharmacy is a business which knows what medicines treat what.

In the case of Passmore in transcript 6 time and direct cost of consultation and transport influenced the decision to buy antibiotics from local pharmacy

Interview transcript 6 “I would have had to pay a consultation fee of 20 dollars”.

Researcher Have you paid for any treatment?

Passmore I have bought some antibiotics for my cough. I just went to the pharmacy and describe my condition and the pharmacist gave me some syrup and antibiotics. I think I paid 7 or so dollars. I did not want to go and see my doctor as I would have had to pay a consultation fee of 20 dollars and the time and effort of going there was not worth it. So for things like that, I just buy from the private pharmacy it's cheaper and you do not worry after transport you just walk to the pharmacy.

5.3.7.6 Working for treatment by young people

At nineteen, Almustafa in interview transcript 15 below and Precious at twenty one in interview transcript 16 above, should possibly be at college or university. This section explains why these young people who should be in tertiary institutions, instead, they are working to be able to pay for their treatment and or diagnostic tests. As Bandara et al (2014), Beegle et al (2006) and Basu and Van 1998) observed households that are unable to offset the transitory income shocks caused by ill-health by using assets as buffer stock resort to child labour (labour substitution axiom).

Interview transcript 15 “I am forced to work”.

Almustafa I pay for the medication myself. I cannot ask my grandmother whom I am staying with to pay for my medication. She is already looking after me and other children besides herself. So I am forced to go to Magaba⁴⁴ to assist the carpenters there with their work in order for me to get money for my drugs.

Researcher How about money for other expenses?

Almustafa They are many. But, the amount I get is about 6 to 8 dollars a day. So I am forced to work up very early in the morning and walk from Ridgeview to Mbare. If I used kombis I would need to pay 5 Rand⁴⁵ to get into town and another 5 Rand to get to

⁴³ In a random exercise the researcher was able to buy various types of antibiotics from different pharmacies in the low and high density which included amoxicillin, ciprofloxacin, clindamycin, cloxacillin, and metronidazole. Except for cotrimoxazole which the Government has permitted could be sold without a prescription, the rest of the antibiotics require a doctor's note.

⁴⁴ A large and dirty informal place, set aside by the Harare Municipal Council for informal craftsman and traders to operate from in Mbare.

⁴⁵ Used as equivalent to 50c.

Mbare, from there I can walk for about 10 minutes to get to Magaba. In the evening I will have to do the same so in the end by walking I save 2 dollars a day.

Researcher How many days a week do you work?

Almustafa Six days?

Researcher How do you get to your treatment?

Almustafa I normally board a Kombi to town and then another to Mbare as where the hospital is far. It is on the other side of Mbare I cannot walk there. If I walked there, I would arrive very late and in most cases would end up not getting all my medication as I would have arrived late. So I end up spending 2 dollars on transport... if my medication is not there, I go to work then after work go to the pharmacy to buy all of it or some of it if I have the money.

Researcher Besides working do you have time to go to school?

Almustafa I cannot go to school when I have to look for money to pay for my tablets and also to get my CD4 count in case they tell us they are not able to do these because the machine is down or something...I like making things from wood and would like to study some engineering course that works with wood.

Chapter Six: Discussion and analysis

6.1 Introduction

This is the first study that investigates treatment seeking behaviour and how this results in direct costs/OPPs, and linking this to coping strategies and the impact on households' livelihoods in terms of physiological and budgetary dimensions. The study explores direct costs/OPPs from the perspective of PLWH using a mixed method approach in sub-Saharan Africa. As there is a paucity of literature in this regard, this study contributes towards knowledge in this area. The findings from this study provide insights on how treatment seeking behaviour patterns that need to be considered for effective interventions to improve treatment coverage are to be developed. The study provides an opportunity to hear from PLWH on what happens when coping strategies are not enough to provide resilience towards direct costs/OPPs.

6.2 Discussion of the quantitative findings

At quantitative level, the study has revealed that in terms of TSB patterns in Harare metropolitan province the respondents used the private health services the most in terms of diagnostic and treatment services. These private health care providers included private laboratories and diagnostic centres, private clinics, mission hospitals/NGOs and private pharmacies, which, cumulatively was n= 262 or 68.4% of the respondents compared to n=121 or 31.6% that used public health facilities (government hospitals and council clinics). In terms of direct costs for diagnostic and other tests both private and public health service providers charged a fee, although they were higher in relation to average household income in the private laboratories (11.4% of average household income) compared to 5.7% of average income with public health service provider. The treatment seeking patterns and costs are similar to those found in the study by Onwujekwe et al (2010) for treatment of malaria by health providers in Nigeria.

Treatment direct costs were borne by n=312 or 81.4% of the respondents and these tend to be costs associated with seeking services from private pharmacies since government hospitals, council clinics and mission hospitals did not charge money while private clinics and private laboratory do not supply ARVs. The quantitative findings show the failure of public health delivery systems in the country, as the resurgence in the number of patients that seek diagnostic and treatment services in favour of the private than the public sector is high.

Zimbabwe has not been able to take full advantage of the Doha Declaration of 2001 that sought to benefit countries that have the capacity for pharmaceutical production of HIV generic drugs. This is largely due to the inability of the government to pay for and avail these drugs in all public and private health entities. It can be argued in some circles as to how the government would be able to subsidise the treatment costs when it was bankrupt and wholly engaged in the land invasion/reform bickering.

In the process, the government scared away both domestic capital and foreign direct investment. It needs to be borne in mind that the country has failed to account for USD15billion accrued in diamond sales over the past decade⁴⁶. In Botswana, for example, revenue from diamond proceeds has been used to fund an extensive and successful ARV programme for free. The crowding out of local pharmaceuticals in favour of generic importations has resulted in shortages being experienced in public health facilities resulting in stock-outs, which predicate the need to seek treatment from subsequent providers at higher cost. To finance treatment seeking behaviour, it can be noted that, n=113 of the study sample or 29% borrowed to pay for treatment while n=104 or 27% sold an asset to pay for treatment. What the study reveals is that communication tools such as cell-phones were most likely to be sold to pay for diagnostic and treatment costs n=73, for clothes it was n=43, domestic appliances fridge n=37 and stoves n= 13. This creates a problem for households if they need to keep things refrigerated or cook. It is also the reason why in some instances respondents were willing to pay in order to avoid the loss of assets, as Ropa in interview transcript 3 reports. While productive assets sold include wheelbarrows or carts n=19, the difficulty in replacing these assets is narrated by Tendayi in interview transcript 12 when he says:

The sale of the cart has affected the way I am able to make a living as I cannot earn money to sustain myself and to buy another one.

Or as in the case of Admire Interview transcript 14, it meant the sale of a wardrobe which has not been replaced to pay for treatment related costs

I sold our wardrobe to a colleague so at the moment we just pile our clothes on those boxes there. Perhaps one of these days I will be lucky and will get enough money to buy another one.

Direct costs associated with transport occurred in accessing both the private and public health services from respondents where (n=241 or 62.9%) paid for transport. The transport costs were unbearable as n=78 or 22.1% borrowed and n=10 or 3.6% sold an asset to pay for transport to access either treatment or diagnostic services. The cost of transport can be attributed to the breakdown of public transport that was cheap and the emergence of private commuter operators as Mamvura and Mashiri, (2009) have observed. Nhelma (2003), Worral et al (2003), Greene (2004), Watkins et al (2004), Mukherjee et al (2006), Ware et al (2006), Rosen et al (2006), Tuller et al (2010), Berutti et al (2012), Joglekar et al (2011), Miller et al (2010) among others contend respectively that transport is a barrier to treatment access which compromises both access to care and ARV adherence by patients. As Tuller (2010:1) states:

⁴⁶ The Herald of 28th April titled "Missing \$15billion looters face probe and the Chronicle of 28th April 2016 titled "Audit into missing \$15billion starts."

The cost of transportation for monthly clinic visits has been identified as a potential barrier to antiretroviral (ARV) adherence in sub-Saharan Africa and elsewhere, although there is limited data on this issue.

The findings of this study reaffirm what the literature has shown that transport can be a barrier towards accessing treatment, as the interview transcript with Almustafa in interview transcript 15 and Passmore in interview transcript 6 explain. This study has been able to quantify the transportation costs and provide explanations from the study respondents of how it affected their access to treatment.

The quantitative part of the study investigated the existence and extent of out of pocket payments in Harare metropolitan province for user fees. In this regard, it found that 301 or 78.6% of the study population paid out of pocket towards user fees. Of these, n=121 or 31.6% were in the public health service arena. This contradicts the government policy which states that PLWH should not pay user fees in public health facilities. This is a manifestation of the health financing issues which can be located in Chapter two, where the Harare City Council's City health department admits that, the reduction in state health support and dwindling development partner support left the local authorities with no alternatives but to use these fees as part of supporting the recurrent expenditure. It's an indication of the market failure where health is no longer a public good. The failure of the state monopoly is also evident through the lack of ability to guarantee health as a public good. In terms of user fees the study reported that n=84 or 22% borrowed money and n=37 or 9.7% sold an asset to pay towards user fees. As noted from the literature, user fees can be an impediment towards accessing health services as has been observed by the Zimbabwe Association of Doctors for Human Rights (2009). Whiteside and Lee (2005) have further noted that user fees are an impediment towards the provision of treatment. This view is shared by Murkhjee et al (2006), Whalton et al (2004) and Weiser et al (2003).

This study found out that, to smooth consumption and ease their plight, respondents either borrowed n=353 (92.2%); or sold an asset n= 284 (74%) due to health shocks. The literature (Sauerborn et al 1996, Jacobs et al, 2012; McIntyre et al, 2006; Kruk, 2009; Russell and Gilson, 2006 and Russell, 2004) indicates this phenomenon. Sauerborn et al (1996:294) note "*The sale of assets was the second common most way to meet health expenditure. For households who did not have sufficient cash...*" However, what is unique to this study is the identification of household assets both by utility in the context of an urban environment that were most likely to be sold and how this perpetuated impoverishment and ill-health.

Ateguba (2012) has argued that health care costs in excess of 40% of non-food expenditure are catastrophic. This standpoint cannot be generalisable as it needs to be noted from the findings from this study. Pradhan and Prescott (2002); Xu et al (2007), Wagstaff and van Doorslaer (2003); Russell (2004); van Doorslaer et al.(2007) have argued that health expenditure directed towards and

within the range of 0% to 10% of household expenditure, as portion or percentage of household expenditure spent on health care, can be catastrophic. Alam and Mahal (2014) have argued for a certain threshold of household 'capacity to pay' as being deemed catastrophic. Doorslaer et al (2006) and Mendola et al (2007:5) have argued for a range of 0.05% for Asian countries and 2.8% for 5 Eastern European countries or using the World Bank poverty line of USD1/day for Asia and USD2/day for the five European countries. Xu (2005), Hortsberg (2003), Trujillo (2003) propose the use of household expenditure as a proxy for income to determine if health expenditure is catastrophic. This argument of a portion of capacity to pay gains credence since quantifying out of pocket payments for health costs when situated in the macro-economic context of the urban population of Harare unemployed population can be problematic. For example, the degree of poverty in Zimbabwe can be noted from the following human development indicators: According to UNDP (2012) 72.2% of all Zimbabweans were considered poor. The UNDP (2012) report further highlights the fact that, of those in paid employment, 94% earned below the total consumption poverty line. In particular, 3 in 4 employed persons are classified as being 'vulnerably employed' UNDP (2012:8). The degree of poverty is further documented by PICES (2011/12:76), which shows that 69.8% of households in Harare are dependent on salary and wages and 27.8% on their own businesses. The PICES (2011/12:79) provides details on the average salaries and wages when it notes that 77% of employed Zimbabwean households earned a gross monthly salary of USD350, with only 4.5% earning above USD800. It is under this context that the various amounts that have been cited for treatment related, laboratory related, transport use, and consultation fees have to be juxtaposed. This also offers the objective explanation for why borrowing and selling of assets was necessary to finance out of pocket payments for health and associated costs. It also explains why cross sectional survey data may not be best in detailing the effects or impact of direct costs/OPPs on households in terms of trying to find out if costs are catastrophic. The proportion of household expenditure spent on treatment costs does not sufficiently show the impact of impoverishment it caused on households.

6.3 Discussion of qualitative findings

The qualitative results of this study provide arguably the most valuable insights on how the above direct cost/OPPs related to diagnostic and treatment affected households at physiological and budgetary levels.

6.3.1 Treatment seeking behaviour

The literature shows how social networks (family, friends and community including institutions such as the church and health services) reinforce stigma. However, the same literature does not show how the social networks can influence treatment seeking behaviour that results in direct costs/OPPs. Bandura (1997), and Hogben and Byrne (1998) have noted that decisions by individuals are influenced by the socio-political and economic environment around them. The social environment has a determinant role in shaping health outcomes at micro, meso and macro levels. At micro level, the

role of social networks has been extensively studied. These networks play a supportive role in the provision of psycho-social support and offer credit facilities in developing countries, (Gregson et al. 2004, Sauerborn et al, 1996, Russell, 2001, 2004; Wilkes et al 1997, Kanji, 1993, Cotton et al 2006, Pargament 2004 and Anderson et al 2009). There has been no documentation of how these social networks influence treatment and or diagnostic treatment seeking behaviour beyond credit and psycho-social support. What this study has shown is that these social networks can be both a source of financial support/credit and can influence treatment seeking behaviour that results in OPPs. That is, individuals are not just passive recipients of credit through social networks as Edd in interview transcript 4, Trust in interview transcript 5, Admire in interview transcript 14 and as Passmore in interview transcript 6 shows:

The thing that made me join the ART programme was the need to extend my days of survival. In adding to my days it has to do with me being able to look after my family. I looked at this issue this way, that if I went down my family will not have any one to look after them. So it was better for me to begin ART so that I can continue to look after my family.

The social networks can be influential when one makes the difficult choice to spend more to access treatment or treatment at all through the desire to get well by averting death. There is the continued need to provide support for immediate family, off-springs and meeting societal expectations about weight loss. A household headed by someone who is an adolescent or someone too old, say above 70 years and does not have a permanent source of income or productive assets is likely to be poor. From the findings of this study it can be noted that, religion becomes a source of influencing treatment seeking behaviour as Shungu in interview transcript 8 and Gogo in interview transcript 2 describe, while Jim in interview transcript 9 show how community perceptions influence such decisions. Family considerations are important when seeking treatment as Ropa in interview transcript 3, Trust in interview transcript 5 and Passmore in interview transcript 6 illustrate. In the case of Edd in interview transcript 4 these social networks (friends) suggest the need to consult alternative treatment in the form of a traditional healer.

The use of traditional healers and medicines by PLWH in Southern Africa has been noted in literature (De Smet et al, 2002, Rodriguez-Fragoso et al, 2002, Babb et al, 2007, Peltzer et al, 2008 and Esther, 2009 and Esther, 2009) to be predominately therapeutic. The literature has been successful in showing the therapeutic benefits and the supply side issues such as commodities and attitudes of health personnel have contributed towards treatment being sought from traditional healers, it has not been able to show how exploitative traditional healers can be. Traditional healers can exact payment in cash or kind from unsuspecting patients' as described by Edd in interview transcript 4 and Gogo in interview transcript 2 who explains this loss as:

I went to N'ganga's some of whom demanded my livestock until I had none left... I sold my cattle and had to offer the traditional healer chicken and goats as part of the sacrifices that had to be made towards my ancestors.

Beyond sources of credit, as this study has shown, social networks are the locus upon which financial resources are mobilised *gratis* as Edd in interview transcript 4 and Ida in interview transcript 18 show. What is significant about the social networks in Ida's case is in highlighting the significance of remittances or capital from kith and kin abroad to pay for health care. There has been little in the literature on how capital generated by those working in the diaspora is helping people left in the continent to access healthcare. There is no literature available on how this form of capital, in the context of HIV/AIDs, is helping to keep PLWH alive. The widespread dependence on remittances from abroad has emerged as a consequence of limited economic opportunities in Zimbabwe owing to what has generally be accepted in some disciplines as bad governance. As Mandaza (2007:5) states

But at no time, either during the armed struggle itself or in this post-independence period, have 'radical' ideologies been meaningfully translated into a practical agenda for the economic and social transformation of the colonial order, including the expansion of the economy through industrialisation programme that increases employment opportunities while adding value to the enormous agricultural and mineral wealth potential.

What this study has been able to show is the significant role that these remittances can play in keeping PLWH alive as Ida in interview transcript 18 demonstrates. Remittances sent home by migrant labourer in the diaspora has become absolutely critical to household survival of those living with HIV. Here, remittances from her sisters and daughter abroad have been important to ensure she receives the best possible health care that is lacking in the public health institutions. This has meant that she is able to regularly attend and receive the best possible quality of care by having diagnostic tests and consultations done using private health providers as health providers of first choice. The consultation fees and treatment costs were paid for by her daughter and sisters who initially took her to a private doctor as her condition demanded. She states:

This could not have been provided in the public health facilities... For all three tests (CD4, LFT and viral load test) to be done I pay USD140. This is done every six months. I also pay the doctor a consultation fee of USD60 every six months for the doctor to prescribe a letter for me to have these done and for the doctor review them.

The remittances have been able to ease consumption in that she has not been able to borrow or resort to hardship financing through the sale of an asset as done by others who are less fortunate than her.

6.3.2 Quality of service (waiting time, stock outs, health staff attitude, stigma)

The quantitative data shows that PLWH opt to use private rather than public health facilities. The explanation that is gathered from the key informant interviews is that most public health facilities, either hospitals or clinics lacked the required prophylaxis such as ARVs or diagnostic equipment as waiting time was compounded by the process in retrieving patient records. This is elaborate in Edd's interview, transcript 4, Shungu in interview transcript 8, Andrew in interview transcript 10, Jim in interview transcript 9 and Admire in Interview transcript 14 high light.

The literature by Lavy and Germain (1994), Collier (2003), Dercon and MacKinnon (2003) and Manangazira (2011) has been able to describe the nature of quality of services, however, it has not been able to show how waiting time, long queues and drug stock-outs affect quality of care. McIntyre and Thiede (2003), Maestad and Mwisongo (2007), Kunihiro et al (2010 and Miller et al (2010) have gone a step further by showing the long queues and drug stockouts. Unlike the aforementioned studies, this study foregrounds how the facets of quality of care result in OPPs and or impoverishment. Patients incurred high direct costs because drugs and or services such as diagnostic services were not available at first provider prompting them to buy from a subsequent provider at higher costs as the interview transcripts with Ropa interview transcript 3, Ida in interview transcript 18, Jim in interview transcript 9 illustrate.

Although equipment for diagnostic tests may be available in some public health facilities, other factors such as lack of electricity forced some of the respondents to seek services at subsequent providers in the private sectors as described by Admire in interview transcript 14. In relation to the literature on quality of service, it needs to be borne in mind that patients require a service that is efficient and effective for it to be deemed as being of quality in delivery. The quality of service as this study has shown is not premised on the availability, type and number of health workers as Sarah et al (1997) have argued as the basis upon which quality health care delivery depends. Rather, the quality of service is premised on how the health staff relates to patients and the availability of an incessant supply of valid drugs. This view is brought out by Passmore in interview transcript 6, who would rather travel 88 kilometres from where he stays to seek services at a public health facility. He states: *"The service is good, the moment you get there they serve you there and there, there is not a time you can really say you spent waiting for ARVs"*. Ida in interview transcript 18 justifies seeking services from a private health provider because the doctor has time to listen. She asserts *"the doctor explains them to me and what I need to do to improve on my CD4 Count and he answers questions without being angry"*. So in discussing the issue of the quality of care, provision of adequate equipment and human resources is not enough if these resources are not patient friendly. Jim in interview transcript 9 says:

I think they are understaffed. I think there is more paper work again they tell you with your card go there and pay. From there you are told to go somewhere the process is long... The workers there do not care about people. Sometimes at 9 o'clock they will take a tea break and they will be no-one to serve you.

Jain (1989) notes the quality of care has to do with how patients are treated by health providers. While the health staff may be friendly, it should not obscure the fact that patients can also be turned away by the perceived quality of drugs. Shungu in interview 8 points out that, '*So I personally believe in having drugs that have a valid date...*'. According to Hosseinipour et al (2006) the quality of medication available is important.

The issue of quality of care is related to bringing services to people in a manner that cuts down on cost of transportation and in an integrated way so that people with multiple infections can receive treatment without paying multiple user charges. For example, as the study has shown, there are two types of queues; one for those with opportunistic infections such as HIV and another for other conditions of ill-health. The provision of integrated services addresses multiple issues, one is at the biomedical level and involves treatment where patients with HIV and other conditions of ill-health like Chamu in interview transcript 1 are attended. Chamu suffers from diabetes which has caused sores to emerge on his feet. This has put him in need of desperate treatment but seems not to be in a position to receive it when he laments that;

When I went to the public general hospital they gave me a list of things that I should bring such as my own dressing, betadine, latex gloves, cotton wool and G.V. paint.

At social and meso levels, the issue of stigma is also addressed in the manner in which services are provided. For example, having patients not segregated by the nature of their illness can assist in building confidentiality and averting stigma. It is difficult to know what the other patients are suffering from, if all are in a single queue. At meso level, the literature (Holstad et al 2006, Obermeyer and Osbone 2007, Steinberg 2008, Turin et al 2008, Deacon 2009, Kanhira et al 2010, Kagee et al 2011 and ZHAAUCT 2013) has not been able to demonstrate how perceived stigma can result in direct costs/OPPs being incurred. What this study has been able to show is that there is a bidirectional relationship between stigma and the difficult choice of spending more to access treatment. The relationship posed challenges to patients and had profound financial implications which sometimes caused impoverishment through asset depletion. Stigma contributes towards direct costs/OPPs as patients lack confidence in public health facilities thereby forcing individuals to opt to buy their own ARVs' as Shungu in transcript 8, Jim in interview transcript 9 and Ida in interview transcript 18 show.

6.3.3 Opportunity cost of waiting time

The time spent in a queue can sometimes be socially disruptive and cause economic discomfort as indicated by the key informant interviews in this study. While the literature has acknowledged that this is a problem, in some instances patients would want to skip queues as noted by Vian et al (2005), Maestrad and Mwisongo (2007), abandon treatment as Kunihiro et al (2010), Miller et al (2010) state, or even incur indirect costs in the form of labour substitution as McIntyre and Thiede (2003) have shown. Russell (2004) and McIntyre et al (2006) argue that patients need to buy food while waiting. The study highlighted the need to earn a wage (productive time) and this can influence treatment patterns as Chamu in interview transcript 1 states:

My friend, I have a target to meet in terms of the money that I need to cash in with my Murungu⁴⁷ of at least 80 dollars a day on the Kombi. So to tell my murungu I spent time queuing for treatment he will either fire me or deduct from my wages and what will I do there are no jobs and I have a family to look after.

In the case of Andrew in interview transcript 10, It is the need to ensure he is able to compete for business when he states *"I have people who need to have their cars sorted; I have to finish repairing them"*. What comes out of these narratives is the predicament of those employed in informal sector who, due to job lay-offs often have to weigh the opportunity cost of receiving a wage and the time spent queuing for treatment when it might not even be guaranteed.

In addition, the study addresses the contentious issue of time spent in the queue which Jim, in interview transcript 9 narrates. He argues that it involves several queues which can be cumbersome:

After they have called your number say P003 that's when you are referred to another queue where you go and pay They stamp your card, then you come back again and join another queue for those receiving their pills. But before that, you have to join another queue for the scale after they finish checking your weight you then collect the ARV's from a small window.

Furthermore the amount spent in the queue and how health staff related to patients can result in them seeking services elsewhere where there is efficiency and confidentiality as noted by Ida in Interview transcript 18 which can result in the loss of self-esteem as she narrates;

Those requiring HIV medication stand in one queue and pregnant or lactating mothers in another queue so you end up with three types of queues. It can be embarrassing, to stand and wait in the queue for those with HIV as most people in the other queues will look at you as if you are cursed or something.

⁴⁷ Slang for boss or employer.

In seeking services it has to be borne in mind that according to behavioural economics, as Chaloupka et al (2003), Vuchinich and Heather (2003) have argued, service delivery includes not just the cost providing goods and services but the time it takes to access them.

Most works leave out the bidirectional relationship of coping mechanism such as transactional sex and or work for treatment by young people as a result of health shocks. The study claims that transactional sex can be a means for paying for treatment. Transactional sex is used to ease household consumption and to pay for treatment seeking behaviour due to health shocks as Sasha in interview transcript 11 explains:

That is why I am forced to go out to nightclubs at night to look for clients who can pay me extra money for me to be able to meet my expenses for my tablets and school uniforms for my son.

This is because the direct costs/OPPs for treatment are beyond what the individuals can afford due to socio-economic circumstances and weak health systems that can be able to provide adequate treatment, care and support. In order to obtain ease and smooth consumption, many women, who lack adequate financial resources to pay for treatment such as those that are unemployed or working in the informal sectors as Sasha in interview transcript 11, will supplement their meagre incomes with transactional sex which, ironically, may be the way they contracted HIV in the first place. The lack of access to formal employment, besides menial income-generating activities increases the susceptibility of women to engage in transactional sex as their health and other social reproductive needs necessitate

The study has shown that work for treatment by young people is a basic and not a luxury axiom as Basu and Van (1998) have proposed. The households cannot overcome their subsistence needs including the need for health care without recourse to child labour. It is important to note that, when young people are forced to work rather than further their education, it limits the development of human resource investment, which once accumulated, cannot be appropriated.

In connecting the critique of transactional sex and work for treatment, it is important to highlight the issue of struggling to pay for treatment that often results in periodic defaulting of treatment due to the nature of work available to the study population. In Zimbabwe, the burgeoning informal sector due to rapid unemployment that can be located in the way the economy has been managed, has meant that people employed in this sector as Chamu in interview transcript 1, Almustafa in interview transcript 15, Edd in interview transcript 4, Trust in interview transcript 4 and those able to be employed as domestic workers as Precious in interview transcript 16 work more as casual workers with no job security or access to acceptable health insurance or protection. Chamu, in interview transcript 1 states; *“They told me AMPTO does not pay for these but I could be assisted without paying the 5 dollars for*

the card". This leaves them without any means to avoid period defaulting on their treatment and in some cases having to put up with multiple infections.

The economic hardships emerge as an issue among people in the informal sector who are forced to pay for ARVs by doing all sorts of jobs '*Kiya Kiya*' to make ends meet; in particular, to be able to at least pay for half of the monthly supply. What is confirmed by this study is that the financial burden that ART related costs place on the household are immense thereby limiting their utility consumption. The impact of direct cost of treatment seeking behaviour due to financial nature on households is described in more detail in this study than has been the case with the literature. Here, the opportunity cost of paying for ARV's amounts to the 'risk' of taking local herbal medicines. In some instances it amounts to total lack of faith and belief in western medicine as revealed in interviews. Transcript 4 asks "ARV's were useful but the problem is they can't eliminate the virus?" Despite their above average literacy and numeracy, traditional beliefs were held in high esteem, by the respondents. These traditional beliefs as narrated in this study interrupted ARV treatment and had the potential to be catastrophic in terms of death or leading to treatment failure which would require strong and expensive ART, which might be a challenge to procure too. The opportunity cost of being on ART compared to traditional medicine is narrated by Edd in transcript 4, as a deciding factor in how and why PLWH would make out of pocket payments. Furthermore, the qualitative information reveals how households due to job casualisation/lay-offs are not likely to forfeit the opportunity to earn a wage in favour of seeking treatment and maintaining the rigour of diagnostic tests that it entails.

6.3.4 User fees

There is need for the government and local authorities to ensure that health facilities have a reliable source of electricity to enable diagnostic equipment to run without disruption. In addition, there is need to ensure that the equipment is maintained, while ensuring that the stock of required medication is maintained and staff are motivated enough to provide the desired quality of care. That is, if the argument for the need of for user fees is to be sustained. At present patients are forced to pay for services that are erratic or not there, which implies that the user fees that are being charged have not been able to improve the quality of well being of patients' without seeking further interventions from the private health providers at an additional cost. While it is the government policy that user fees are not charged to PLWH, on the contrary, the amounts charged in public health facilities vary depending on the provider of health service to the public from USD5 in government hospitals and USD1 in council clinics. In interview transcript 9 Jim states: "*After you have paid the dollar, they stamp your card*". What this amount of money collected is used for is not apparent given the lack of services available at these institutions which force patients to seek services in the private sector. In the private sector, patients are charged more than they are just in public hospitals for diagnostic and treatment

services. The fact that there is no discernible improvement in services amplifies the need to scrap user fees as they seem not to be used to improve patient welfare. The argument by Fredrick et al (2001), Akin et al (1987), James et al (2006), Mahal and Veerabhraiah (2005) that user fees are a source of supplementary health financing, that help to dampen consumption and improve consumption efficiencies in health care fall away as this study has shown.

6.3.5 Willingness to pay for services

The willingness to pay should be seen at two levels. At one level, Kruk et al (2009) point out that it is not synonymous with ability to pay. According to the qualitative data n=353 or 92.2% borrowed and n=284 or 74.1% sold an asset to pay for treatment related costs. Of significance is the fact that, 74.1% of the study population sold an asset to pay for treatment. The very act of having to sell an asset, in most cases, that was productive illustrates that payment for treatment is not by choice. Even in cases where key informants did indicate their willingness to pay for services as Shungu in interview transcript 8 and Ida in interview transcript 18, this decision was more to do with the need for 'perceived quality of health services' obtaining in the private health sector.

The need to safeguard property by minimising its loss can, in some cases, influence treatment seeking behaviour patterns as Ropa in interview transcript 3 indicates. This issue is not mentioned in the literature and yet it can significantly influence treatment seeking behaviour patterns by forcing patients to make the difficult choice to seek treatment at a higher cost in the private sector as Ropa in interview 3 narrates. What needs to be investigated is how access to property and the need to safeguard it has forced others to seek treatment in the private health sector.

As a result of these conditions it can be seen that health provision is selective and restricted by availability of cash for example to have laboratory test done and improving quality of life through supplementary medication. What is also poignant from the narratives is the catastrophic consequences caused by lack of money to buy ARV's such as skipping tablets and resorting to traditional medicine. Self-treatment has become a phenomenon due to the direct costs/OPPs of consultation/user fees as noted in the findings of this study which led respondents to buy pills over the counter. This is consistent with the other researches by Piette et al (2004) Gotsadze et al (2005), Goudge et al (2009) and Onwujekwe et al (2010). The study notes that other medical conditions among PLWH are going unattended. In addition, pill rationing leads to periodic defaulting through skipping taking treatment. According to the bio-medical literature, this can result in sub-optimal treatment or treatment failure which has been warned against in the management of asymptomatic and symptomatic of HIV as Reynolds et al (2003), El-Khatib (2011) and Wang et al (2011) have documented. This can also result in the need for more expensive efficacious treatment regimes being required often obtaining from the private sector thus increasing the direct costs of treatment.

6.3.6 Coping strategies

In this section the description by respondents on the challenges faced when borrowing and or selling an asset as an option for hardship financing of health are elaborated. What needs to be noted is the fact that if used on their own, the quantitative findings on this aspect of hardship financing above do not show the difficulty of pursuing this course of action nor the impact it had on exacerbating poverty. This difficulty is particularly more for those in the informal sector whose income is unpredictable. Another financing mechanism used to support out of pocket payment for ART was through the sale of assets, which are difficult to replace as Admire in Interview 14 explains *“replacing sofas at the moment is not a priority as there are other needs like food, clothing for the children in my case as you can see; this work suit is also what I wear even if I am not working.”* While the literature (Jacobs et al, 2012; McIntyre et al, 2006; Kruk, 2009; Russell and Gilson, 2006 and Russell, 2004) has shown how the sale of assets to finance health can lead to impoverishment it has not been able to show what assets are sold in an urban environment. The study has shown that communication tools such as cell-phones are likely to be sold and that while they may be seen as communicative tools they do go beyond this function to be productive assets as in the case of Almustafa in interview transcript 15 has illustrated and as Nyahoda (1993) observe.

The effects of coping strategies such as asset depletion and impact on household go beyond what the literature has been able to demonstrate. The findings of the study have shown how the direct cost/OPPs associated with treatment seeking behaviour affect physiological needs of households and impact on household budgets. What have been documented are the effects of ill health on household capacity to reproduce in terms of food security (Russell, 2004; McIntyre et al, 2006 and Alam and Mahal, 2014). There has not been any documented evidence on how direct costs/OPPs associated with treatment seeking behaviour affect the physiological needs of households such as the dietary composition as shown in interview transcript 3 by Ropa and in interview transcript 14 with Admire in terms of the detail of the types and frequency of meals.

It is in this context that, the need for social and health insurance becomes compelling to smooth household consumption as the findings have shown. The findings on coping strategies and their dialectical link to impoverishment is similar to those of Xu et al (2003), Gertler and Grubler (2002), Russell (2004), (O'Donnell et al, 2005; Adam and Xu et al (2008), O'Donnell et al. (2005); Gerter and Gruber, (2002), McIntyre et al (2006), Alam and Mahal (2014) among others. What distinguishes this study from those above on coping strategies such as borrowing and selling of assets is the fact that patients may not be able to be resilient enough. They, therefore, resort to transactional sex, opt for unproven treatment through traditional health seeking, cope with multiple untreated infections and work for treatment by young people. However, the social costs caused by anxiety and uncertainty cannot be quantified in monetary terms, but there is a need to off-set these as well when one considers

interventions that need to be put in place. The policy consideration includes the need for health insurance for the working population, the unemployed and people in the informal sector (self-employed) too, to off-set the costs of out of pocket payments. The relief expressed by respondents when the burden of out of pocket payments for ARV's and laboratory costs was lifted by health insurance is compelling as key informant interviews with Chamu interview transcript 1, Gogo interview transcript 2 and Ropa interview transcript 3 demonstrate.

This highlights the need for policymakers who inform the Country's prevention and treatment campaigns that, these issues need to be critically examined as they arise due to a multiplicity of factors. The crisis of capital accumulation erodes the ability of the health systems to respond effectively to the supply and demand side of health service provision. The need to address these problems lies in addressing the wider structural context which is obscured by the biological and behavioural pathologies which miss the cause of the problem. The prevention agenda promoted by Zimbabwean state premised on prevention and safe sex can be problematic as the study has shown. Here both men and women become susceptible to unsafe sex practices due to the need to survive. The crisis of accumulation has caused the post-white settler state to fail to effectively tackle the root cause of poverty, unemployment, lack of economic growth and development. That would have ensured adequate financing of the health system and the reduction in untreated multiple infections and transactional sex as a way to cope with the multi-dimensional effects of poverty and ill-health identified in this study.

6.4 Limitations

I have identified the following limitations in the study, namely:

1. Using PLWH as the basis for (quantitative data collection) distribution and collection of the questionnaires selection bias could have been introduced. As there could be PLWH who are not members or are not known by the main stream civil society organisations of PLWH.
2. Some of the questionnaires had missing data pertaining to personal details of informants pertaining age, sex, occupational and marital status of the respondents which would have been useful in mapping out the socio-demographical characteristics of the respondents. However since this study does not seek to establish the link between the socio-demographic variables to treatment seeking and direct costs of treatment this oversight did not affect the main thrust of the study. The study participants in some areas could have been reluctant to provide such personal information for fear of perceived retribution on the way they had answered the questions.

3. The qualitative analysis was not without its shortcomings, largely due to the following; it was based on those participants who had indicated willingness to be interviewed when the questionnaires were administered.

Notwithstanding the above, it should be noted that the above limitations did not deviate the main purpose of the study. The study sought to:

1. Identify the treatment seeking behaviour patterns, direct cost/OPPs of seeking treatment, the coping strategies and the effects this has on the livelihoods and households. The study skirted out how socio demographic characteristics of PLWH influenced treating seeking behaviour patterns or influenced the difficult choice in paying for treatment?
2. Establish how the direct costs of treatment seeking behaviour result in poverty and on breaking household resilience.
3. Get more precise socio-economic data of how treatment seeking behaviour affects the livelihood of PLWH through quantitative and qualitative data.

Chapter Seven: Conclusions and policy recommendations

7.1 Conclusion

The facets of health system such as access, user fees, health insurance and the quality of care have a strong bearing on where treatment is sought and the difficult choice patients make to pay for treatment. Furthermore, it has been shown in this sequential mixed method study that socio cultural factors equally contribute to the difficult choice that patients make to seek treatment. This sometimes necessitated coping strategy to smooth consumption through the borrowing and selling of assets. Asset depletion affects household livelihoods in the way they are able to socially reproduce themselves. Nyahoda (1993) points out that the new information and communication technologies have changed the way relations of productions are shaped. However, resilient coping strategies were not adequate necessitating the need for other means to be taken, which include, opting for traditional medicine; transactional sex, and periodic defaulting of treatment. Defaulting treatment results in sub-optimal treatment results and future treatment failure, self-treatment, coping with multiple unattended infections and work for treatment by young people. Thus, human resource and capital formation are interrupted, the progress towards development stalled and poverty further exacerbated. The need to invest in treatment at affordable prices cannot be further underscored. The inability of adults to access treatment, as illustrated in the findings has resulted in the negation of embodied capital. That is, the age which should be economically productive in terms of skills and competences is not able to fulfil its productive function due to treatment costs and as they opt for unproven treatment solutions. The work for treatment by young people has meant that the potential for physical capital accumulation is diminished. Young people are forced to work instead of acquiring skills at tertiary institutions. The study has also shown that the political and economic conditions that fashion the way social relations of production are defined are central in the definition of what type of health system will prevail. For HIV strategies to work effectively in bringing down infections as the study has shown, there is need for behavioural/cultural interventions to take cognisance of the under pinning materialist/structural causes and explanations for HIV. What this study has shown is that economic and normative realities are interdependent; behavioural choices cannot be abstracted from the material environment in which they are made.

The issue of direct costs associated with treatment seeking behaviour patterns is shaped by both the health systems and the socio-cultural contexts in which treatment is provided. A holistic approach towards universal health coverage will ensure no one is left behind in the agenda to end AIDS by 2030. The strengthening of health system will entail among other actions:

- Putting in place adequate measures that bring services in an integrated manner closer to people, reduction of transaction costs of accessing and providing health services;

- Provision of social health insurance to smooth consumption and ensure access to continued education by off spring embodied capital;
- Provision of quality of health care that ensures supply related issues are addressed and long waiting time associated with accessing services is reduced.

The showing of the entanglement of treatment and diagnostic seeking behaviour to direct costs/OPPs and impoverishment will help contribute towards policies that limit universal treatment coverage and result in poverty. This improves the well-being of households' livelihoods, by providing optimal ways in which health services can be delivered without causing impoverishment. In addition, social-cultural factors such as stigma and discrimination that result in treatment seeking behaviour will also need to be addressed. It is on the basis of this conditionality that the policy recommendations in the next section are constructed upon.

7.2 Policy recommendation and future research agenda

7.2.1 Bringing integrated quality services closer to people

There is need for an integrated approach towards the provision of health services to PLWH to include counselling and testing and the provision of curative care beyond just HIV. This does not only reduce the transaction costs of providing health care as evident in a vertical approach to health care provision. Rather, counselling and testing help in reducing stigma in the provision of services. Embedded in this is the need for patient confidentiality which should not be sacrificed. Here, future research will need to explore how integrated service delivery can be provided in a cost effective and efficient manner while not negating patient confidentiality. Inefficiencies of an institutional nature have also contributed in making out of pocket a costly alternative.

7.2.2 Strengthen diagnostic and treatment capacity in public sector

There is need to strengthen the diagnostic and treatment capacity in public health service institutions. This will ensure that patients do not incur costs associated by not being able to access the required services at the first provider without going to a subsequent one usually at higher cost. This means that the supply side issues associated with diagnostic and treatment (competent human resources and commodities) are affordable to meet the demand. Further research should illuminate how capacity constraints related to human resources and commodity supply chain can be overcome in a limited resource setting.

7.2.3 Wider application of Results Based Financing (RBF)

The adoption of RBF has had significant success in reducing maternal and infant mortality in Zimbabwe. The success of RBF can perhaps be widened to include HIV and other opportunistic infection targets. The use of RBF can be the fulcrum to improve quality of care, in particular, making available commodities, reduce waiting time and improve conditions of service of health personnel.

However, there is need for future research to investigate how RBF can be cascaded beyond improving maternal and infant mortality care to PLWH. Out of pocket payments for treatment related costs constituted a significant portion of the household budget. The crisis of accumulation brought about by lack on capital investment and savings can be mitigated through use of performance based contracting. Shifting from input to output based financing using both conditional and unconditional cash transfers and vouchers can help to alleviate poverty due to health shocks caused by HIV. Greater involvement of the private sector through public and private partnerships can help improve and provide better health delivery (reduction of queues). The partnership can lead to a reduction in patients who resort to unproven yet cheap traditional herbal remedies.

7.2.4 Social Health Investment Fund

Social protection through the provision of safety nets for PLWH are hardly debated given the macro-economic environment where domestic aggregate demand for goods and services is low and the economy is restricted in resources. The government through state and development partner support can provide vouchers to enable PLWH to access transport or other forms of services in both the public and private health facilities.

There is need for a social health insurance scheme that can help to smooth consumption including strengthening the BEAM and making the AMPTO system acceptable for health payment. One way is through the creation of a social investment case modelled on the successful health and HIV investment cases that have mobilised additional resources for the health and HIV sector. Such a social investment fund would provide complimentary resources mobilised from both domestic and external sources, to increase coverage of Basic Education Assistance Module (BEAM) beyond just paying school fees for HIV orphans. BEAM can be extended to cater for vulnerable members of society in general. This would reduce the issue of patients who resort to transactional sex to ensure they are able to afford the basic necessities for social reproduction. The AMPTO system will need to be effectively guaranteed to ensure that patients' do not contend with multiple infections, self-treat and resort to periodic defaulting or work towards treatment. The need to explore the use of conditional and unconditional cash transfers to mitigate the impact of impoverishment caused by health shocks needs to be investigated. As noted by Govender (2011), Lund, Noble, Barnes and Wright (2008) and Barrientos and DeJong (2006) such mechanisms can help keep young people in school while ensuring they have access to the required treatment.

Future research will need to focus on how investing in social security for PLWH through a sustainable social investment fund can be operationalised and how efficiently funds from such a fund can be disbursed. There is need to ensure that mobilised funds are not abused by the elite. Research will also need to investigate how the problem of affordability and accessibility can be addressed in a fragile economic context which has a large unemployed and informal sector population.

7.2.5 Addressing stigma

There is need for more sensitisation about HIV/AIDS, and this includes re-examining how society relates to the issue of HIV without its sexual or moral connotations. There is need to look at the way HIV/AIDS education is taught in schools, but more importantly, debates and discussions should be encouraged. Central to this discussion and debate is the ‘sexual’ connotation of HIV/AIDS, which will need to be deconstructed if HIV/AIDS is to be normalised as any other chronic illness, as Decock and Johnson (1998) suggest. This way, its treatment and care can be more open and out of pocket payments will become unnecessary, because the illness will no longer be considered shameful. Research will have to come up with innovative ways in which HIV without its sexual or moral connotations can be taught in schools and discussed in public. This would also address the delay in accessing treatment due to stigma.

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Annexes

Annex 1: MRCZ Approval Letter

Telephone: 791792/791193
Telefax: (263) - 4 - 790715
E-mail: mrc.zimbabwe@yahoo.com
Website: <http://www.mrcz.org.zw>



Medical Research Council of Zimbabwe
Josiah Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL LETTER

Ref: MRCZ/B/401

22 February, 2013

Phillip M. Nyahoda
University of Bath
United Kingdom

RE:- The Political Economic Constructions of ill-health: The Case of informal payments by people in Particular Circumstances in Harare Metropolitan Province, Zimbabwe.

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review

- a) Research Protocol
- b) Research Protocol Summary
- c) Informed Consent Form (English)
- d) Statement of consent to be Photographed, Audiotaped or Videotaped

• **APPROVAL NUMBER** : MRCZ/B/401

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF MEETING** : Expedited
- **APPROVAL DATE** : 22 February 2013
- **EXPIRY DATE** : 21 February 2014
- After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ Website should be submitted three months before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Website.
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Website is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Website.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrc.zimbabwe@yahoo.com or mrcz@mrcz.org.zw
- **Other**
- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH

Annex 2a: Consent letter for questionnaires

Dear Participant,

I am a Doctoral student at the University of Bath School for Health in the United Kingdom and I am carrying out a study titled **“The Political Economy of health: The Case of Out of pocket payments by People living with HIV in Harare Metropolitan Province, Zimbabwe.”**

The broad objective of this research project is to investigate the nature of informal/out-of-the-pocket payments and the effects they have on the delivery of quality of health care to people living with HIV and AIDS in Zimbabwe. Specifically, it seeks to generate a blueprint and model for improving health services delivery for people living with HIV and AIDS.

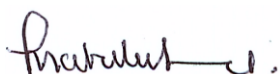
The purpose of this letter is to ask if you would like to take part in the study. Although you will not get any direct benefits for participating in the study the information obtained during the study will help to develop a blueprint focuses on, among other things, factors that constrain access to antiretroviral drugs in the public health facilities.

I will gather the information from people living with HIV and AIDS through focus group discussions and key informant interviews with policy makers. The interviews will take place in the home, the school, community centre or any other suitable place; wherever it is convenient. The Staff at these places will not know who is taking place in the study so should you decide to take part you will remain anonymous.

If you consider taking part in the study it would be most appreciated. However, if you do not wish to be involved in the study your decision will be accepted and you do not have to give any reason. Even if you agree to participate in the study, you will be free to withdraw at any time without needing a reason.

You may discuss this decision with anyone you wish, such as a family member, friend or support group members, do not hesitate to contact me on 0712413280 if you have any questions.

Yours sincerely



Phillip Matululu Nyahoda

Annex 2b: OPPs Questionnaire

Questionnaire ID			
	District	Ward	Household
Location of interview (i.e. suburb).			
Venue of interview (i.e. house, health centre, association).			
Occupation of informant	Age of informant	Marital status of informant	Education of informant
Date of completing questionnaire			
	Day	Month	year

1.1 Kindly indicate how you paid for the following tests below?

Type of Test	Yes=1 No=0	Amount paid	Form of payment i.e cash/ medical Aid
1. HIV			
2. CD4 count			
3. Liver function			
4. Other tests (specify)			

2. ARV treatment drugs

2.1 Are you receiving anti-retroviral treatment?

Yes		No	
-----	--	----	--

2.2 Is anti-retroviral treatment free?

Yes		No	
-----	--	----	--

2.3. Which line of ART treatment drugs are you on? (*i.e. 1st or 2nd line*)

2.4 If yes how do obtain and pay for them?

2.5 If no how do you pay for treatment?

2.6.1 Have you borrowed any money to pay for your treatment?

2.6.2 If yes how much?

2.6.3 Why did you borrow any money?

2.6.4 Have you had to sell any of your assets (land, livestock, crops, personal belongings to meet your medical expenses?

2.6.5 If yes indicate what you sold?

2.6.6 What did you use the money for?

2.6.7 Have any relatives, friends and neighbours provided you with support during period you were unwell due to side effects of the drugs?

2.6.8 If yes what kind of support did they provide you with?

2.6.9 Did you pay for this/these service(s)?

2.6.10 If yes how much did you pay?

3 Outpatient visit(s) expenses

3.1 In which facility did you make those visits (up to a maximum of 3 visits)?

Facility used	No. of visits in past 4 weeks	No. of visits in past 8 weeks	No. of visits in past 12 weeks	Did you pay out of pocket for services?	Approximately how much did you pay?
Government facilities					
1. Health centre					
2. District hospital					
3. Provincial Hospital					
4. Central hospital					
Mission Facilities					
5. Mission hospital					
Local Authority Facility					
6. Hospital					
7. Clinic					
Private sector					
8. Private clinic					
9. Private pharmacy					
10. Traditional healer/faith healer					
11. Laboratory/radiology centre					
12. Charitable NGOs					
13. Other (specify)					

4. Transportation

4.1 How did you get to the facility indicated above?

Means of travel	No. of visits in past 4 weeks (Indicate frequency)	No. of visits in past 8 weeks (Indicate frequency)	No. of visits in past 12 weeks (Indicate frequency)	How much did you pay?
1. Walked (ask why)				
2. Bicycle				
3. Public transport				
4. Private Taxi				
5. Friend gave me a ride				
6. Relative gave me a ride				
7. Own car (fuel cost)				
8. Asked someone to bring me medication				
9. Other (specify)				

8. Have you ever defaulted on taking ARV's drugs? (if yes ask why?)

5. Alternative medicine costs

5.1 Have you consulted either a faith healer/traditional healer for treatment in the past 12 months?

5.2 If yes? Why did you need their services?

5.3 How did you pay for your consultation/treatment?

6. Cost of Treatment

6.1 Can you tell me how much you paid for the following did?

Means of treatment	In past 4 weeks (Indicate amount)	In past 8 weeks (Indicate amount)	In past 12 weeks (Indicate amount)
1. Consultation fee			
2. antiretroviral drugs			
3. Tuberculosis drugs			
4. Antibiotics			
5. Other opportunistic infection drugs.			
6. X-Rays			
7. Laboratory tests			
8. Other expenses excluding transport specify			
Total amount			

6.2 Who paid for the above treatment (Cash/Medical Aid/free)?

6.3 How was payment made?

6.4 Have you ever defaulted on ART treatment?

6.5 If yes, what was the reason?

7.a **Would you be willing to take part in a more detailed key informant interview?**

Yes		No	
-----	--	----	--

b. Please provide your contact details

Thank you very much for your cooperation and time in participating in this interview. Do you have any questions?

Annex 3: Consent letter Interviews

25th June 2013

Dear Participant,

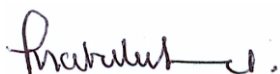
I am a Doctoral student at the University of Bath School for Health in the United Kingdom and I am carrying out a study titled **“The Political Economy of health: The Case of Out of pocket payments by People living with HIV in Harare Metropolitan Province, Zimbabwe.”** The broad objective of this research project is to investigate the nature of informal/out-of-the-pocket payments and the effects they have on the people who want to access health services. In particular it is to find out the factors that inform your decisions to pay out of pocket for treatment.

The purpose of this letter is to ask if you would like to take part in the study. Although you will not get any direct benefits for participating in the study the information obtained during the study will help to make suggestions on improvements can be made improve quality and availability of drugs and services. Develop a blueprint focuses on, among other things, factors that constrain access to antiretroviral drugs in the public health facilities.

Should you consider taking part in this study in would be most appreciated. However, if you do not wish to be involved in the study your decision will be accepted and you do not have to give any reason. If you agree to participate in the study, you will be free to withdraw at any time without needing a reason. The interviews will take place at place of your convenience. This research has been approved by the Medical Research Council of Zimbabwe, see attached approval.)

You may discuss this decision with anyone you wish, such as a family member, friend or support group members, do not hesitate to contact me on **0712413280** or **263774462336** if you have any questions.

Yours sincerely



Phillip Matululu Nyahoda

Annex 4: Information about Taking part in the study

Study title: “The Political Economy of treatment seeking behaviour and factors influencing Out of Pocket Payments by People Living with HIV in Harare Metropolitan Province, Zimbabwe.”

You are being asked to take part in a study for a Doctoral Research. Here is some information to help you decide whether or not to take part. Please take time to read through the following information and discuss this with any one you may wish to consult such as your peers, family member or support group. Please ask me if there are any issues that you need clarification on or you might require further information.

1. You will not get any direct benefit from participating in the study. However information obtained from this study will help to develop a blueprint focuses on, among other things, factors that constrain access to antiretroviral drugs in the public health facilities.
2. It is up to you to decide whether or not to take part. If you decide to take part you will be given information sheet and consent form, to say you wish to take part in the study. If you do not wish to be involved in the study your decision will be accepted and you do not have to give any reason. Even if you agree to participate in the study, you will be free to withdraw at any time without needing a reason.
3. The interviews and focus group discussions will be tape recorded, however, all the information collected during the study will be kept confidential and you will not be identified by staff helping to process the data or anyone by it.

Study title: “The Political Economy of treatment seeking behaviour and factors influencing Out of Pocket Payments by People Living with HIV in Harare Metropolitan Province, Zimbabwe.”

What is the purpose of the study?

This study is being undertaken as part of my Doctoral Research or thesis requirements and its objective is to investigate the nature of informal/out of pocket payments and the effects they have on the delivery of quality of health care to people living with HIV and AIDS in Zimbabwe. Specifically, it seeks to generate a blueprint and model for improving health services delivery for people living with HIV and AIDS.

Why have you been chosen?

You have been chosen because as a member of a support group of people living with HIV and AIDS you have a better understanding of how out of pocket/informal payments affect the quality of health of people living with HIV and AIDS. Also the study specifically would like to know the experiences of how out of pocket payments/informal payments can be minimized so as to improve the quality of health.

Who is organizing the research?

This study is part of my Doctoral Thesis by me Phillip Matululu Nyahoda, a University of Bath School for Health Student, .It will last for just over 3 months, beginning in February and ending in April.

What will happen to me if I take part?

If you decide to participate in this study, you will only need to do one interview. The interview will last for about an hour, but may be shorter or longer depending on how much you want to say. The interviews will take place in the home, the school, community centre or any other suitable place; wherever it is convenient and comfortable. I shall undertake to pay for any travel expenses for the study. The interviews will be tape recorded and typed on the computer after the interview to enable easy of processing.

What might I not like about the taking part in this study?

You may experience some emotional upsets by talking about this topic, however, expressing emotions and taking things through collectively can be beneficial.

What are the benefits of taking part in this study?

Information obtained from this study will help to develop a blueprint focuses on, among other things, factors that constrain access to antiretroviral drugs in the public health facilities. It is further envisioned that the outcomes and possible implications of this research will be to:

1. Track and collate the various informal/out-of-the-pocket expenses incurred by people living with HIV and AIDs in Zimbabwe.
2. To detail how informal/out-of-the-pocket expenses have impeded access to quality of health care in particular of treatment by people living with HIV and AIDS as a social movement in Zimbabwe.
3. Provide a framework and model for improving the quality of health care service delivery for persons living with HIV and AIDS in Zimbabwe.

What if something goes wrong during the study stop?

In the very unlikely event that anything should occur during the study, causing harm or injury to your self, I am unable to offer any payments or compensation for the harm.

Who will know I am taking part in the study?

All information which is collected about you during the study will be kept confidential. The staff who might be called upon with the recording and processing of the data that you will provide will not know you as your name will be changed in the study so that you can not be identified.

Local Research Ethics Committee.

This study has been approved by the Research Council of Zimbabwe, who can be contacted on 263-4-791792/791193

What will happen to the results of the study?

The results will be written into thesis which will be submitted to the University of Bath School for Health. Examples of what you said in the interview could be used to explain your experiences of how informal payments have affected the quality of your health. However, your name will be changed and you will not be able to be identified. Copies of the tape recordings will be destroyed so that no body else is able to listen to them.

Contact information

Should you wish to get more information about this study please contact:

Phillip Matululu Nyahoda

4 Megawatt Court, 119 Josiah Tongogara Avenue

Harare

Zimbabwe

Mobile: 0712413280

Email: matululup@yahoo.com

Thank you for reading al this information, please ask if you have any questions.

Annex 5: Consent Form for signing for the qualitative interviews

Study title: “The Political Economy of treatment seeking behaviour and factors influencing Out of Pocket Payments by People Living with HIV in Harare Metropolitan Province, Zimbabwe.”

Please tick the box if you agree with the statements.

1. I confirm I have read and understood the information sheet ☐
2. I understand that the participation in this study is voluntary and that I am free to withdraw from the study at any time. ☐
3. I agree for the interview to be tape recorded and typed but understand that my identity will be kept confidential. ☐

_____	11/07/2013	_____
Name of person	Date	Signature

_____	____/____/____	_____
Researcher	Date	Signature

Annex 6 a: Out of Pocket Payment In-depth Interview introduction

Guidance for introducing yourself and the purpose of the interview:

- Good morning/afternoon. My name is Phillip Matululu Nyahoda and I am a Doctoral student at the University of Bath, School for Health in the United Kingdom.
- You are among those chosen from a list of all those who volunteered to be interviewed for this study. As part of my doctoral research project, the purpose of this interview is to obtain information about the informal or out of pocket expenses that you have incurred over the past 12 months and how they have affected the quality of your health.
- This interview is voluntary and you can choose not to take part. The information that you give will be confidential. There will be no way to identify that you gave this information. The information will be used to prepare my final doctoral report, but will not include any specific names.
- Could you please spare some time (around 50 minutes) for the interview?

NB to enumerator: This survey is NOT part of the registration exercise and will have no influence on your status as a beneficiary/non beneficiary.

- If you can allow me I shall be using both my personal digital assistant and tape recorder to assist with the recording.

Annex 7 b: In-depth Interview Guide

Background:

I am interested in finding out how and why you paid for treatment and laboratory related services. This is a follow up to the questionnaire that you completed last year. I need additional information to support the quantitative data and to understand better why you pay for services and how this has affected you.

Informant background:

	Gender	Age	Employment	Marital Status	Education	Residence
Notes						

Treatment and care related costs:

From a previous study done it was found out that PLWH are paying out of pocket for treatment related service; why and how do you decide to pay on your own out of pocket”?

1. What are the main reasons why you paid for treatment and or Laboratory and or X-ray?
2. How much did you pay? (what was your source of money)?
3. Did you borrow? Why? How (How and why of doing it)?
4. Did you sell an asset to pay for treatment (why and how of doing it)?
5. How has paying for treatment affected your livelihood?

